The second edition of *Paediatric Nursing in Australia: Principles for Practice* brings the important care of the child and young person to life, by equipping students with essential knowledge and skills to become informed and capable partners in the nursing care of children, young people and their families across a variety of clinical and community settings.

The text develops students’ critical thinking and problem-solving skills by exploring contemporary issues impacting on the health of children, young people and their families.

This new edition features the latest research and case studies, coupled with reflection points and learning activities in each chapter. Further resources, including links to video and web content, multiple-choice questions and critical-thinking problems, are available on the updated instructor companion website at [www.cambridge.edu.au/academic/paediatricnursing2e](http://www.cambridge.edu.au/academic/paediatricnursing2e).

Written by a team of experienced nurses within the field, *Paediatric Nursing in Australia* is grounded in current care delivery and is an essential resource in preparing future nurses for practice in paediatric settings throughout Australia.

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Preface

We hope that you find this second edition of *Paediatric Nursing in Australia: Principles for Practice* useful as a contemporary primary resource for pre-registration students of nursing as well as new graduates practising in Australian paediatric settings. The second edition maintains a strong Australian focus. We have incorporated feedback from students, educators and our academic colleagues to improve each chapter and hope you are pleased with the result. We are most grateful to Cambridge University Press for offering to support us to publish the second edition.

The second edition of this text first sets the context within which student nurses can expect to practise paediatric nursing in Australia. It presents the profile of child health, illness and injury within Australian communities and includes details of national health trends for children and young people in Australia, in comparison with international trends.

Emphasis is given to evidence-based paediatric nursing assessment, nursing care and nursing interventions in paediatric settings. This includes acute care, complex care, care of the child with a chronic illness and childhood mental health care.

We are most appreciative of the superb effort of our contributing authors in sharing their expertise in this second edition. Sincere thanks to Robyn Galway, Ibi Patane, Robyn Rosina, Loretta Scaini, Lindsay Smith, Helen Stasa, Nerralie Shaw and Julia Taylor once again for their time and effort in creating this second edition of *Paediatric Nursing in Australia: Principles for Practice*. 
Jennifer Fraser, Donna Waters, Elizabeth Forster and Nikki Brown
1
Australia’s children and young people

Donna Waters

Learning objectives

In this chapter you will:

- Be introduced to the demographic profile of Australia’s children and young people and the measures used to monitor their health and wellbeing

- Gain a sense of the current health and wellbeing of children and young people living in Australia

- Consider existing and emerging threats to the health and wellbeing of Australia’s children and young people within a global context

- Reflect on your knowledge of the health and wellbeing of Australia’s children and young people, and how you might use this knowledge in your work as a nurse
Introduction

This chapter examines the health of children and young people growing up in Australia. The aim is to consider children and young people in a more global context and as the future population of Australia. We will look at population characteristics, challenges to healthy growth and development, and emerging health and social trends. We will also define and describe some of the measures (or indicators) of children and young people’s health referred to throughout the text.

The future role of the paediatric nurse is not only shaped by emerging physical threats such as childhood obesity, injury and chronic illness, but also by behavioural, developmental and mental threats resulting from the rapid social and environmental change affecting children and young people all over the world. We invite you to consider the idea that the health and welfare of the children and young people of Australia are as much determined by the context of the past and present as they will be by the context of the future.

As you read more widely about the health and wellbeing of children and young people, you will become aware of many different definitions and descriptors for age groups within this population. The Australian Bureau of Statistics (ABS), for example, defines children as those aged under 15 years of age and young people as being 15–24 years of age. In Australia, legal adulthood is established at 18 years of age, and the ABS defines young adults as being in the age range 18–34 years.

In this text, infants, children, adolescents and young people approaching adulthood (up to 18 years of age) collectively constitute the group defined as Australia’s children and young people. We will use the age range 0–4 years to describe the period of infancy and early childhood, 5–12 years as childhood and 13–18 years as adolescence.
Australia – the ‘lucky country’?

According to the major indices of a successful society, Australia ranks as one of the best places to live in the world. The population of this somewhat isolated continent – the sixth-largest land-mass in the world – enjoys health, housing, nutrition, income, civil rights and a strongly performing economy. A comparatively small total population of 24 million people clusters towards the moderate climates and highly urbanised areas of the east coast, with more than 11 million Australians settled in the largest cities of Melbourne, Sydney and Brisbane.

Aboriginal Australians inhabited the continent for tens of thousands of years before colonisation by the British in 1788. After centuries of discrimination and exploitation, Aboriginal and Torres Strait Islander peoples now make up less than 3 per cent of Australia’s population. While the government formally apologised to Aboriginal Australians in 2008 for years of discrimination and injustice, Aboriginal Australians continue to experience high rates of illness, unemployment and imprisonment.

Australia’s current political orientation is towards Asia, but a rich and complex immigration history has woven itself into the fabric of a country that is now home to people from over 140 countries. With the gradual dismantling of the White Australia policy in the years following World War II, the 1950s saw the arrival of mainly European migrants seeking to build a better life for their families, especially their children. Around 72 per cent of Australia’s population was born in Australia. In 2012, the majority
of permanent migrants to Australia were from the United Kingdom, the People’s Republic of China, India, the Philippines and Vietnam.

Australia’s children and young people

Indicator measurement

Before we take a look at the many reports published about the current and future state of the health of children and young people in Australia, it is useful to provide a quick update on some demographic and statistical terminology. The use of a common international language for the measurement and tracking of health indicators allows for the comparison of global data over time and between countries. In Australia, government agencies routinely collect data on the health and wellbeing of the population. The best known of these agencies are the ABS and the Australian Institute of Health and Welfare (AIHW). In addition to conducting the national Census of Population and Housing every five years since 1911, the ABS collects a wide range of demographic and statistical data to inform future planning by the Commonwealth government.

Advances in technology and data capture have enabled health data agencies to significantly increase the transparency and sophistication of data recording, and to improve accessibility to organised and standardised sets of health indicators. It is now common to find companion documents or large appendices to indicator reports outlining the rationale for the choice of a unit of measurement (for example, average over one year); definitions of numerators and denominators for rate-based calculations;
and reporting of centiles, summary statistics (mean and median) and measures of spread or variation (standard deviation) to facilitate comparison with other data. While rate-based statistics are mostly used to describe population-level data, various clinical indicators are also used in Australian hospitals for measuring trends and variations in the quality and safety of health care (ACHS 2015).

The routine measurement of standardised internationally recognised indicators of health and wellbeing over time is extremely useful because health indicators can:

- offer a snapshot of the health of a community or group at a single point in time
- enable long-term tracking of the health of specific populations or groups
- monitor upward and/or downward movements or trends over time
- measure the impact of specific health interventions such as health-promotion strategies
- use past information to predict (or model) what might happen in the future
- facilitate international comparisons (benchmarking).

In addition to the routine collection of Australian health data, health indicators also enable us to compare the health and wellbeing of Australian children and young people with those of other children growing up in countries similar to ours. For example, it is very common for government reports to compare statistics for Australia against those of countries who share membership of the Organisation for Economic Cooperation and Development (OECD). It is of note, for example, that for data collected in
2011, the OECD Family Database (OECD, 2015: 2) names Australia among the four OECD countries with the highest proportions (14–18 per cent) of children living in jobless families.

Table 1.1 defines indicator measures for some of the 19 common health priority areas identified as key national indicators (or headline indicators) for describing the health, development, wellbeing and welfare of children and young people in Australia.

**Table 1.1 Example of key national health indicators for children and young people**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Indicator</th>
<th>How it is measured (per year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality</td>
<td>Infant mortality: Number of deaths of infants less than 1 year of age in a given year</td>
<td>Rate per 1000 live births</td>
</tr>
<tr>
<td></td>
<td>Sudden Infant Death Syndrome (SIDS)</td>
<td>Rate per 100 000 live births</td>
</tr>
<tr>
<td></td>
<td>Death rate for children 1–14 years</td>
<td>Rate per 100 000 children</td>
</tr>
<tr>
<td>Morbidity</td>
<td>Proportion of all children (0–14 years) diagnosed with asthma</td>
<td>Percentage of all children with asthma 0–14 years</td>
</tr>
<tr>
<td>Health Category</td>
<td>Description</td>
<td>Reference</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>New cases of type 1 diabetes</td>
<td>Among children 0–14 years</td>
<td>Rate per 100 000 children</td>
</tr>
<tr>
<td>New cases of cancer</td>
<td>Among children 0–14 years</td>
<td>Rate per 100 000 children</td>
</tr>
<tr>
<td>Disability</td>
<td>Proportion of children aged 0–14 years with severe or profound core activity limitations</td>
<td>Percentage of all children 0–14 years</td>
</tr>
<tr>
<td>Injuries</td>
<td>Age-specific death rates from all injuries for children 0–14 years</td>
<td>Rate per 100 000 children</td>
</tr>
<tr>
<td>Overweight and obesity</td>
<td>Proportion of children whose BMI is above international cut-off point for ‘overweight’ or ‘obese’, adjusted for age and sex</td>
<td>Percentage of all children</td>
</tr>
</tbody>
</table>

Source: Adapted from AIHW (2011a).

Note that this table illustrates our first example of how different definitions and descriptors are used for reporting on health trends within age groups. The AIHW *Children’s headline indicators* report (AIHW, 2011a) describes results for 12 indicators of health and wellbeing for
children 0–12 years of age. The AIHW also offers a dynamic online tool for viewing 18 of the headline indicators by group such as age, family type and remoteness. Another report, *A picture of Australia’s children* (AIHW, 2012), describes outcomes on similar indicators, but defines children as those aged 0–14 years, while an earlier report, *Making progress: The health, development and wellbeing of Australia’s children and young people* (AIHW, 2008), focused on children and young people up to 20 years of age. It is therefore important to look at the characteristics of groups included in each data set before attempting to compare indicator results across groups.

**Mothers and babies**

If you were born in Australia in 2014, you were one of 12.8 births per 1000 population, were slightly more likely to be male (105.1 males to 100 females born) and were likely to be one of the three out of four babies born in the most populous states of New South Wales, Victoria or Queensland. With only 2.9 neonatal deaths per 1000 live births per year (4.1 per 1000 infants), and a stable maternal mortality rate of fewer than seven deaths per 100 000 per year, it is expected that you would have survived your birth. You are likely to have access to nutritious food, will grow normally and generally be healthy. Living in a culturally diverse, stable and democratic society, you will attend school and live a long life (average 81.2 years). Being born in Australia in 2014, you contributed to a population growth of 1.4 per cent per year and joined a diverse Australian population with an estimated net migration rate of 5.65 migrants per 1000 population (AIHW, 2015a).

Further, as a baby born in Australia, it is likely that (AIHW, 2012, 2015a):
Children and young people

In June 2015 (ABS, 2015a), the total number of children under 15 years of age living in Australia was 4.48 million, comprising 19 per cent of the total population. In 2015, the estimated resident population of young people entering adulthood (turning 18 years of age) was 153 613 males and 146 078 females, a ratio of 105.16 males to every 100 females (ABS, 2015a).

The overall number of children in Australia doubled between 1925 and 1995 (an increase of 2.4 million). Most of this growth occurred after

- your mother is 30 years of age or older (in 1991, the average age of women having their first baby was 27.9; in 2013, it was 30.1)
- you weighed an average of 3.3 kilograms at birth and were born within a normal weight range between 2500 and 4499 grams (although 6.4 per cent of you weighed less than 2500 grams and were considered to be of low birth weight)
- you were delivered vaginally in a hospital following a spontaneous labour (although 33 per cent were born following a caesarean section and 18.4 per cent of your mothers elected to have this procedure without first going into labour)
- you were conceived naturally, but for 3.6 per cent your parents will have received some form of assisted reproductive technology (Li et al., 2012)
- half of you (46 per cent) were exclusively breastfed up to 4 months of age, with rates falling to 14 per cent at six months
- approximately 92 per cent of you were fully immunised by 1 year of age.

**Children and young people**

In June 2015 (ABS, 2015a), the total number of children under 15 years of age living in Australia was 4.48 million, comprising 19 per cent of the total population. In 2015, the estimated resident population of young people entering adulthood (turning 18 years of age) was 153 613 males and 146 078 females, a ratio of 105.16 males to every 100 females (ABS, 2015a).

The overall number of children in Australia doubled between 1925 and 1995 (an increase of 2.4 million). Most of this growth occurred after
World War II, when there was not only a rise in the birth rate, but also high levels of migration of young couples with children to Australia. A small increase in fertility also occurred between the mid-1980s and mid-1990s, when the Baby Boomer generation reached child-bearing age. Since then, fertility rates have generally been below the level required to replace the Australian population.

Despite these small increases in the total number of children, a reduced fertility rate combined with increased life expectancy and lower migration all add up to proportionally fewer children in the Australian population at the current time. As in other developed countries, the trend is for the proportion of people aged 65 years and over to increase by 2.8 percentage points (from 13.6 per cent to 16.4 per cent between 2010 and 2015), while the proportion of Australian children is projected to decline from 18.9 per cent to 17.6 per cent during the same period. Proof of this trend already exists, with the proportion of children decreasing from 36 per cent of the total population in 1925 to 22 per cent in 1990 and 19 per cent in 2012, with further decline to 17.6 per cent projected in 2015 (ABS, 2013b). The most recent 2016 census will inform future projections.

Figure 1.1 compares the age distribution of the Australian Aboriginal and Torres Strait Islander population with the non-Aboriginal and Torres Strait Islander population of Australia. The Aboriginal and Torres Strait Islander population is characterised by higher fertility and mortality rates than the general Australian population. In the most recent analysis of population data in 2006, children and young people (defined as 0–24 years in this example) represented more than half (57 per cent) of the total 517,000 Aboriginal and Torres Strait Islander people in Australia. Children under 15 years of age comprised 38 per cent of this population, compared with only 19 per cent of the general population (ABS, 2011a). These powerful numbers clearly place Aboriginal and Torres Strait Islander
children and youth at the core of their family, culture and community relationships. The median age of the Australian Aboriginal and Torres Strait Islander population in 2006 was 21 years, compared with a median age of 37 years for other Australians.

![Figure 1.1 Comparison of Aboriginal and Torres Strait Islander population with general population of Australia, 2006](image)


**Australian families**

The demographic characteristics of 6.3 million Australian families reported in the 2009–10 Family Characteristics Survey (ABS, 2011c) reveal that 44 per cent were couple families with resident children. Just over 40 per cent of families had no resident children of any age and 14 per cent were sole-parent families with resident children. Of the 6.3 million families included in the 2009–10 report, 40 per cent (or 2.5 million) were migrant families demonstrating very similar characteristics (46 per cent couple families with resident children and 10 per cent sole parents). More migrant families live in multi-family (4.5 per cent) or group households (3.8 per cent) than Australian-born persons (2.3 per cent) (ABS, 2011c).
Many Australian women are delaying having babies until later in life, and are increasingly requiring assistance to become pregnant. Forty-seven per cent of mothers over 40 years of age and 42.5 per cent of those choosing to deliver in a private hospital will have their baby delivered by caesarean section. What implications does this have for nurses working in neonatal and paediatric care settings?

The proportion of children and young people in the Australian population is declining while the proportion of adults over 65 years is increasing. What impact might this have on health funding, and on the wealth and wellbeing of Australians in the future?

Children and young people (to the age of 24 years) constitute 57 per cent of the total Aboriginal and Torres Strait Islander population. What mechanisms do Aboriginal and Torres Strait Islander peoples have for participating in the design and delivery of health-care services to their communities?

More than 25 per cent of those in the Australian population are born overseas. Working as a paediatric nurse in one of the most diverse countries in the world may challenge you. What challenges have you encountered as a child growing up in Australia? How could you apply this knowledge to your work as a nurse?
young people

A snapshot

Case Study 1.1 referred to Australia’s international reputation as the ‘lucky country’, and generally Australian children are healthy and well. But there are large variations between health indicators for children living in remote or socially disadvantaged areas, between Aboriginal and Torres Strait Islander children and those in the general population, and even between the various states and territories of Australia. Different health indicators are also important at different points in the lifespan. For example, infant mortality is an internationally recognised indicator of health and wellbeing in infancy. This is because a child’s risk of death is greatest at the time of birth and during the first year of life (AIHW, 2012). Similarly, birth weight, breastfeeding and immunisation rates are indicators of a healthy early childhood (0–4 years) (AIHW, 2008). As children grow, injury and chronic diseases pose more serious risks, and as they enter adolescence (13–18 years), indicators of mental and physical health are likely to include overweight and obesity, sexually transmitted infections, sleep disorders and/or mental health problems associated with real-time or cyber-bullying, substance use, and injury or violence (AIHW, 2008, 2011b).

The economic and social situations of the families and communities in which children and young people grow up – for instance, access to healthy food, employment, child care, parental health, disability and homelessness – are important determinants of future health. Similarly, indicators of childhood safety and security (injury, child abuse and neglect, children as victims of violence, and juvenile crime) sit alongside indicators of learning and development, which again vary across the lifespan. While early childhood education, literacy and numeracy rates, and youth
participation in university education or work, are equally important indicators of the wellbeing of children and young people, educational outcomes are not the focus of this text.

A number of major reports on child and youth health have been commissioned by the Australian government over the past five years, and no doubt others will have been completed by the time you read this text. This section draws on data from mainly government data collections and reports to paint a picture of the current health and wellbeing of Australia’s children and young people.

**Mortality**

Infant and child mortality rates are strongly associated with economic advantage and social determinants of health – access to clean water, nutritious food, a safe environment and health care. In Table 1.1, we outlined some of the common national indicators for measuring the general health status of children and young people in Australia. Mortality – especially infant mortality – is significant as one of few indicators that are routinely measured by OECD countries and that feature in most international comparisons of the health of children.

**Infants**

More than two-thirds of infant deaths in Australia occur in the first 28 days after birth (during the neonatal period) and almost half of these occur on the day the baby is born (AIHW, 2012). Despite this, a number of factors have contributed to Australia’s progress in significantly reducing infant mortality over the past 30 years. These include improved effectiveness of and participation in maternal antenatal care, better nutrition and the
advantageous economic and environmental climate enjoyed by the majority of Australians (see Case Study 1.1).

Australia’s infant mortality rate is currently 4.1 deaths per 1000 live births, a reduction from 8.8 deaths per 1000 live births recorded in 1986 (AIHW, 2012). Almost half of all infant deaths (46 per cent) are due to perinatal conditions (complications occurring during pregnancy or birth); a further 26 per cent are due to congenital anomalies and malformations. While hypospadias (a defect of the male urethra) was the most common congenital anomaly reported in Australian infants in 2002–03 (Abeywardana & Sullivan, 2008), conditions of the heart and circulatory system were the most common malformations causing death. The remaining infant deaths are due to a range of mostly undefined abnormal signs and symptoms, including Sudden Infant Death Syndrome (SIDS).

Infant mortality rates vary across populations. In remote and very remote areas of Australia, the infant mortality rate is almost twice that of babies born in major cities at 6.8 per 1000 live births, and is similar for Aboriginal and Torres Strait Islander infants (7.2 deaths per 1000 live births) when based on combined data for New South Wales, South Australia and the Northern Territory (AIHW, 2012). A comparison of infant mortality in OECD countries in 2012 (OECD, 2013) revealed that infant mortality was highest in Mexico (14.1 deaths per 1000 live births) and lowest in Japan (1.1 deaths per 1000 live births), with Australian infant mortality rates equivalent to the OECD average.

Neonatal intensive-care units, with their associated specialised technology and staff, combined with improved communications and emergency flight retrieval systems, have contributed significantly to reducing neonatal deaths. Beyond birth, increasing awareness of national immunisation schedules and SIDS prevention through national health-promotion campaigns has contributed to reductions in vaccine-preventable
diseases in infants, and reduced the rate of sudden and unexpected death in infants less than 1 year of age during sleep, previously known as ‘cot death’. In 2010, the mortality rate from SIDS was 27 deaths per 100 000 live births, or 7 per cent of total infant deaths; almost three-quarters of these were male infants.

**Children**

The death rate for children aged 1–4 years of age (19 deaths per 100 000 children) is almost twice that of children aged 5–9 years or 10–14 years (both 10 per 100 000) (AIHW, 2012). This is attributed to higher rates of injury and comorbidities from congenital conditions affecting this age group. However, the *Making Progress* report (AIHW, 2008) shows that the mortality rate of Australian children under five years of age is equal to the OECD average. Cancers and accidental drowning each account for three deaths per 100 000 in children aged less than 4 years (AIHW, 2008: 7).

Among Aboriginal and Torres Strait Islander children, the mortality rate of 25 deaths per 100 000 population is twice as high as the Australian average for children 0–14 years (13 per 100 000), but this rate is even higher for children living in remote or very remote regions (31 deaths per 100 000). Despite this, the rate of all childhood deaths (regardless of age group) has declined by an average of 52–60 per cent since 1986. This is largely due to reduced child mortality from traffic accidents, and coincides with the introduction of child safety seats in cars, as well as strict seatbelt and drink-driving legislation in Australia. While injury remains the leading cause of death (34 per cent) for Australian children, cancers (17 per cent) and diseases of the nervous system (11 per cent) also contribute significantly. It is of note that while death by suicide is relatively rare in
children under 15 years of age (0.4 per 100 000 children), 17 of the 52 suicide deaths occurring between 2007 and 2011 in this age group were Aboriginal and Torres Strait Islander children (ABS, 2011b).

**Young people**

The independence of adolescence introduces a whole different set of risks to the health and wellbeing of young people aged between 15 and 18. Injuries from traffic or workplace accidents, the harmful effects of alcohol and other drug use, and mental health problems are the leading causes of death in this age group.

In 2011 (ABS, 2011b), more than one-quarter (27.8 per cent) of all male deaths in the 15–24 years age group were due to suicide. In 2006, transport accidents and self-harm resulting in suicide accounted for 11 and five deaths per 100 000, respectively (AIHW, 2008). Unlike any other age group, mortality rates for male adolescents are twice as high as those for females of the same age. Between 2005 and 2009, the number of deaths among Aboriginal and Torres Strait Islander youths aged between 15 and 24 years was almost three times higher than for the non-Indigenous population. The mortality rate for young Aboriginal and Torres Strait Islander people during this period was 115 deaths per 100 000, compared with 41 deaths per 100 000 for young people of the same age in the general population (AIHW, 2011a).

**Hospitalisation**

The Australian government nominates a range of health conditions (National Health Priorities) that are of specific relevance to the Australian population because of the burden these conditions place on the daily lives of families and communities, and their impact on the economic
sustainability of the country. While reducing injury has been a National Health Priority since 1986, common chronic conditions affecting both adults and children in Australia (asthma, diabetes and cancer) collectively account for 20 per cent of the burden of disease among children aged 0–14 years (AIHW, 2012). The impact of chronic conditions is often measured by hospitalisation rates (or hospital separation rates), as this provides an indication of the burden of illness experienced by the child or young person and their family.

Importantly, the monitoring of hospitalisations also determines the need for future health services in Australia, such as training needs for paediatric specialists in nursing, medicine and surgery, as well as demand for hospital, operating and intensive care beds, and for community clinics and outreach or home care. Considering that 37 per cent of Australia’s children and young people had at least one long-term condition in 2007–08, and that this equates to more than 1.5 million children, you can start to see why chronic conditions of childhood are important (ABS, 2009).

**Injury**

Injury clearly contributes to mortality in children and young people, but injuries are also responsible for a significant number of admissions to hospital within these age groups with an overall rate of 1785 per 100 000 population (Pointer, 2014). During a 12-month period (2011–12), more than 130 000 children and young people were hospitalised with injuries, with boys twice as likely to be admitted than girls. Consistent with the mortality rates discussed above, the highest rates of hospitalisation due to injury during this period were among males aged 18–24 years – largely due to unintentional transport injuries and assaults – and among those
living in rural and remote regions, or of Aboriginal and Torres Strait Islander descent.

Drowning and thermal injuries (burns) were the most common injuries requiring hospitalisation in infants (less than 12 months) and young children (1–4 years); however, unintentional ingestion of poisons and falls from playground equipment still constitute major risks to young children. During 2011–12, rates of injury due to falls were highest among the 5–9 years age group (701 per 100 000 population), again mostly due to climbing equipment (Pointer, 2014). Falls also accounted for 8703 hospitalisations among 10–14-year-olds in 2011–12, with 15 per cent of these cases involving skateboards. Unintentional transport injuries, self-harm and assault become more prevalent as causes of injury in this age group, and by 15–17 years of age, the AIHW (Pointer, 2014) reports the rate of hospitalisation for intentional self-harm at 302 cases per 100 000 population. This rate is four times higher in females and most commonly involves intentional self-poisoning (Pointer, 2014).

A further snapshot of the type of injuries leading to the hospitalisation of Aboriginal and Torres Strait Islander children and young people was conducted for the period 2011–13. During these two years, 18 537 Aboriginal and Torres Strait Islander children and young people were hospitalised due to injury, with the age-standardised rate higher among Aboriginal and Torres Strait Islander males (2982 cases per 100 000 population) compared with 2023 per 100 000 for Aboriginal and Torres Strait Islander females (Pointer, 2016). The highest rates of injury were observed in older age groups for both sexes, with an increased rate of injury associated with increasing remoteness from around 10 years of age.

The most common cause of injury among Indigenous children and young people of all age groups up to 15 years was falls, again involving playground equipment in the younger age groups. Assault was the leading
cause of hospitalisation in the 15–17 and 18–24 years age groups, with the rate of 457 cases per 100 000 population being six times higher than that for all Australians (Pointer, 2016).

**Chronic conditions**

It may seem unusual to associate chronic conditions with children and young people, but chronic diseases have the potential to interrupt normal growth and development, and to produce immediate and possible long-term effects on physical, emotional and social wellbeing. These impacts – especially on normal growth and development – are frequently overlooked as the unintended consequences of a chronic illness and its long-term treatment.

The range of chronic conditions affecting children and young people is broad, and includes those resulting from neurological congenital anomalies such as spina bifida and neural tube defects, cardiac defects such as transposition of vessels, Tetralogy of Fallot and gastrointestinal, renal and limb deficits. Genetic conditions (Trisomy 13, 18 and 21, phenylketonuria and cystic fibrosis) also constitute an important burden for Australia’s children and young people, and around 7 per cent of Australian children aged 0–14 years also have a disability of some kind. The most common types of disability are intellectual disabilities (affecting an estimated 161 000 children, or 3.9 per cent) and sensory or speech problems (affecting an estimated 119 000 children, or 2.9 per cent) (AIHW, 2012). All chronic conditions will impact on the way a child lives, grows and functions within their society.

We will briefly explore three of the more commonly encountered chronic conditions affecting Australia’s children and young people – common not only because of their prevalence, but also because they
collectively account for the highest number of hospitalisations. As a paediatric nurse, you will likely have the opportunity to care for children and young people who have one of these conditions.

**Asthma**

Asthma affects 10.8 per cent of the Australian population (approximately 2.5 million people (ABS, 2015b) and therefore asthma is also the most common long-term condition affecting children and young people, with 10 per cent of Australia’s children (0–14 years) reported to have asthma in 2007 and 2008 (ABS, 2009). While there are acknowledged gaps in the collection of population statistics for childhood asthma in Aboriginal and Torres Strait Islander communities, data collected between 2012 and 2013 (ABS, 2013a) indicate that one in seven (15 per cent) Aboriginal and Torres Strait Islander children aged 0–14 years were affected by asthma, representing a 3 per cent higher prevalence of asthma (14 per cent) in 2004–05 in this population and hospital separation rates estimated at 589 per 100 000, compared with 506 per 100 000 for children in this age group in the general population. Asthma is thought to be associated with environmental and lifestyle factors, although there is no difference in asthma prevalence between children growing up in a remote area or in a major city. At the same time, the prevalence of asthma is slightly higher among those children living in areas of low socioeconomic advantage (AIHW, 2012).

While placing a considerable burden on the child and family, asthma can be managed with appropriate preventative treatment and medication, and fortunately deaths directly attributable to asthma are quite rare (1.5 deaths per 100 000 population across all age groups in 2013), except for Aboriginal and Torres Strait Islander people, whose asthma mortality rate
was 2.3 times higher during the same period (AIHW, 2014a). The prevalence of asthma was highest in Australia during the 1980s and 1990s, but this trend has reversed, with age-standardised rates dropping from 13.5 per cent of all children aged 0–15 years during this decade to the current prevalence of 10 per cent (ABS, 2009). Asthma prevalence is highest among children aged 5–9 years (13 per cent), and is higher in boys (16 per cent) than girls (10 per cent).

Following this trend, hospitalisation rates for asthma decreased by one-third between 1998–99 and 2006–07, to 331 per 100 000 children in the 5–12 years age group (AIHW, 2011a). However, asthma separations still account for 4 per cent of all child hospital admissions, or more than 21 000 children per year.

Because indicators of the presence of asthma vary across the world, international comparisons can be difficult. For example, one study of 6- and 7-year-old children that defined asthma as the presence of wheeze over the previous 12 months (ISAAC, 2011) showed that prevalence rates in both Australia (20 per cent) and New Zealand (22 per cent) were above the global average of 11.5 per cent.

**Diabetes**

The key national indictor for diabetes is the number of new cases (or incidence) of type 1 diabetes among children aged 0–14 years (see Table 1.1). According to the Australian National Diabetes Register, the incidence of new cases of type 1 diabetes increased from 19 per 100 000 in 2000 to 22 per 100 000 (equivalent to 913 new cases) in 2009 (AIHW, 2012). This increase occurred mainly before 2005 and rates have remained relatively stable at 10 to 13 cases per 100 000 population since (AIHW 2015b). Of the 2323 new cases of type 1 diabetes diagnosed in 2013, more than half
were children and young people (under 18 years) (AIHW, 2015b). The incidence of type 1 diabetes also increases with age: children in the 10–14 years age group are 2.6 times more likely to be diagnosed with diabetes than children in the 0–4 years age range (AIHW, 2012). Consequently, older children are 4.7 times more likely to be hospitalised than those under the age of 5 years (AIHW, 2012). Put another way, in 2013, rates of diabetes were three times higher among 0–14 year olds (at 24 per 100 000 population) than in those aged over 15 years, with eight per 100 000 population (AIHW, 2015b).

Interestingly, while the incidence of type 1 diabetes is higher among males – especially in the 10–14 years age group (35 and 26 per 100 000 respectively) – rates of hospitalisation are higher for females.

While type 1 diabetes accounts for the majority of childhood cases, estimated at more than 5700 children in Australia (AIHW, 2015c), there is early evidence to suggest that type 2 diabetes is increasing among children. This has been associated with increased levels of obesity and physical inactivity among Australian children and young people (AIHW, 2014b).

As surprising as it may seem, there are few reliable estimates for the incidence of type 1 diabetes across geographic regions of Australia, by remoteness, family socioeconomic status or for Aboriginal and Torres Strait Islander children. In 2008, the prevalence of type 1 diabetes in those aged 0–14 years was 138 cases per 100 000 population, but this ranged from 62 per 100 000 children living in the Northern Territory to 188 per 100 000 living in Tasmania (AIHW, 2015c). Between 2001 and 2013, rates of type 1 diabetes across all age groups were lower in remote and very remote regions compared with other areas of Australia – seven cases per 100 000 population compared with 11–13 per 100 000, respectively (AIHW, 2015b) and between 2005 and 2013, Aboriginal and Torres Strait Islander people had a lower incidence of type 1 diabetes than other
Australians: seven per 100 000 population compared with 10 per 100 000 respectively (AIHW, 2015b). This is reflected in hospital data revealing that separations for type 1 diabetes were lower for Aboriginal and Torres Strait Islander children aged 0–14 years than for all Australian children (52 and 74 per 100 000, respectively), and were slightly higher in major cities compared with remote and very remote regions (67 and 66 per 100 000 children). While the incidence of type 1 diabetes does not appear to be strongly associated with the social, economic and environmental conditions of childhood, it is of interest that hospital separations were 34 per cent higher for children with type 1 diabetes living in lower socioeconomic conditions than for those living in higher socioeconomic areas (AIHW, 2012).

The International Diabetes Federation (IDF) is an alliance of more than 200 diabetes associations in more than 160 countries, which publishes an atlas of the latest global and regional diabetes statistics (IDF, 2013). According to the IDF, the incidence of type 1 diabetes in the 0–14 years age group in Australia is similar to that in the United States and United Kingdom; all three countries rank above the OECD average incidence of 17 per 100 000 children. Korea has the lowest incidence of type 1 diabetes in the 0–14 years age group (1.1 per 100 000 children), while Finland has the highest (58 per 100 000).

Cancers cause significant morbidity and mortality in children, and were collectively responsible for 17 per cent of deaths in those aged 1–14 years between 2008 and 2010 (AIHW, 2012). However, cancer is not just one disease, and in children the site of origin and course of illness can be very different from adult cancers. Acute Lymphoblastic Leukaemia (ALL) is
the most common, accounting for 4.2 per cent of all cancers in children, with the next most common being cancers of the brain (1.9 per cent) and non-Hodgkin lymphomas (0.9 per cent) (AIHW, 2012). A brief update on cancer in Australia (AIHW, 2014d) estimated that among those in the 0–24 year age group in 2014, there would be 1540 new cases of cancer and 180 cancer-related deaths. While this number is low compared with other age groups, cancers remain a leading cause of death in Australia’s children and young people.

Survival is used as a key indicator to measure the effectiveness of cancer treatments, specialised cancer services and early detection. Between 2004 and 2010, five-year survival for all cancers affecting Australian children aged 0–14 years was 81 per cent. While this represents a massive improvement from 68 per cent cancer survival during the mid-1980s, there are differences across cancer type and age group. Five-year survival from ALL, for example, had improved from 73 per cent in the mid-1980s to more than 90 per cent by 2012 (Hunger et al., 2012).

Another key national indicator for cancers is the number of new cases (or incidence) among children aged 0–14 years (see Table 1.1). During the period 2004–08, an average 583 new cases of cancer were diagnosed in this age group. This equates to an incidence rate of 14 per 100 000 children, a rate that has remained relatively unchanged since the last major data collection in 1999–2003, and that is commensurate with more recent estimates of incidence in the 0–24 years group (AIHW, 2014d). There are also differences in cancer incidence across age groups. Children aged 0–4 years are almost twice as likely to be diagnosed with cancer (21 per 100 000) than older children (10–12 per 100 000). Between 2010 and 2011, cancer accounted for around 7000 hospital separations – mostly boys (57 per cent) aged 0–4 years – as indicated by incidence rates in this age group (AIHW, 2012).
Australia has similar rates of childhood cancers to those found in the United States and Canada, and ranks 25th of the 33 OECD countries for incidence of childhood cancers and slightly above the OECD average of 13.4 new cases per 100 000 children. Germany has the highest incidence of childhood cancers (20.6 per 100 000) and Poland has the lowest incidence (5.6 per 100 000).

Again, there are few reliable national estimates for the incidence of cancer in Aboriginal and Torres Strait Islander children. However, hospital separation data reveal lower rates of hospitalisation for Aboriginal and Torres Strait Islander children aged 0–14 years compared with all Australian children with cancer (114 and 164 separations per 100 000, respectively). Perhaps unsurprisingly, five-year survival rates for cancer were higher for children living in major cities (81 per cent) compared with those living in outer regional (78 per cent) and very remote areas (75 per cent) of Australia. Hospital separation rates were also higher for those living in major cities. There are no statistically significant differences between cancer survival rates for children of high or low socioeconomic advantage (AIHW, 2012).

### Reflection points 1.2

- Across OECD countries, around 57 per cent of children live in households where all adults are in work. Australia, Hungary, the United Kingdom and Ireland have the highest number of children living in households where no adult is in paid employment. What social, economic, geographic or demographic factors might explain why Australia is on this list?
Emerging health priorities

Children’s mental and physical growth and development are constantly challenged by transitions that occur both within their family and community, and through increasingly broader engagement with their social world through school, sport and the media. Indeed, challenge and change are important for transcending many of the normal developmental stages.

- Aboriginal and Torres Strait Islander children, as well as both Aboriginal and non-Aboriginal children living in remote and very remote regions of Australia, are twice and three times respectively more likely to die than the average Australian child. What factors do you think contribute to the higher child mortality rate of these populations?

- How are measures of incidence and prevalence different?

- What do you notice about the relative incidence and prevalence of asthma, diabetes and cancer? How does this relate to the actual number of Australian children with these chronic conditions? How would you account for differences in incidence between Aboriginal and Torres Strait Islander populations compared with all Australian children and young people?

- Disability can be a result of a sensory, intellectual or mental impairment. It can also result from the treatment or chronicity of common childhood disorders such as the three discussed above. What disabilities do you think might arise from living with asthma, diabetes or cancer?
of personhood. We have briefly looked at some of the common health threats to children and young people, and now look at some of the areas emerging as priorities for the health and wellbeing of Australia’s children and young people in the future. The first (overweight and obesity) is somewhat obvious, as it is a frequent topic of media and public health research. The second (dental health) is perhaps less obviously related to health, but is important because of potential associations between gum disease, healthy nutrition and the development of chronic disease in later life. Social and emotional wellbeing is named as one of the 19 national headline indicators for children’s health, development and wellbeing (AIHW, 2011a), but no national data are currently available for this indicator. As social and emotional wellbeing refers to the way children and young people feel about themselves and others (including their approach to stress), this third emerging health priority will be discussed under the topic of mental health (also see Chapter 7). Obesity and mental health are national health priority areas for all age groups in Australia.

**Overweight and obesity**

While it is desirable that children’s weight increases as they grow, excess weight gain will result from long-term imbalances between energy consumed and energy expended. We are all familiar with the social, cultural, environmental and economic drivers behind what is increasingly called the ‘obesity epidemic’. This essentially results from increased consumption of high-energy foods and beverages, and reduced physical activity. Parenting practices have a significant impact on establishing healthy eating patterns and promoting physical activity in early childhood. A survey of 880 000 Australian children aged 5–12 years in 2008 showed that 42 per cent did not participate in any organised sport or dancing over
the two-week data-collection period (AIHW, 2008). Being overweight or obese significantly increases the risk of developing serious and chronic health conditions such as asthma, cardiovascular disease, cancers and type 2 diabetes in both children and adults. In addition to increased stress on growing bones and joints, there can be significant associated self-esteem, behavioural and social impacts for children and young people who are overweight or obese. Obesity was named as a National Health Priority in 2008, and obesity prevention forms part of Australia’s National Preventative Health Strategy (NPHT, 2009).

**Body mass index (BMI)** is the most common measure of overweight or obesity. While BMI is not a direct measure, like height or weight, international cut-off points based on age and sex are used to determine the number of children who are overweight or obese in any given population. In 2007–08, it was estimated that 23 per cent of Australian children aged 5–14 years had a BMI score above international reference points for being overweight (17 per cent) or obese (6 per cent) relative to their age and sex (AIHW, 2011a). This equates to a staggering 430 000 children in the 5–14 years age range, or 500 000 aged 5–17 years – approximately one in every four children and young people (ABS, 2009).

There are no major differences in the numbers of overweight and obese children born in Australia or overseas, between boys and girls, or between children who live in couple or sole-parent families (AIHW, 2011a), but children living in the lowest socioeconomic areas are 1.7 times more likely to be overweight or obese (31 per cent) compared with same-aged peers in the highest socioeconomic areas (18 per cent) (AIHW, 2012). There appear to be slightly fewer overweight or obese children living in Tasmania compared with other states and territories of Australia, and in 2004–05, Aboriginal and Torres Strait Islander teenagers (15–19 years) were 2.6 times more likely to be obese than other Australian
teenagers (AIHW, 2008). However, it is not possible to fully explore differences in overweight and obesity because of limited height, weight and socioeconomic indicator data available for children growing up in remote areas and in the Northern Territory. Internationally comparable data for children and young people are also scarce. A comparison of 15-year-old children living in 11 OECD countries between 2003 and 2007 ranks Australia as having the seventh highest rate of overweight and obesity (24 per cent of 15-year-olds) compared with the OECD average of 23 per cent (AIHW, 2011a).

There is considerable potential to reduce the adult health burden by preventing children from becoming overweight or obese, and the importance of establishing healthy eating and exercise behaviours in children should not be under-estimated. However, media reports suggesting that the childhood ‘obesity epidemic’ is out of control may be somewhat exaggerated. In a review of 41 studies reporting BMI in children and young people aged from 2–18 years, Olds et al. (2010) conclude that trends in the prevalence of childhood obesity in Australia may have plateaued. Their meta-analysis shows almost no change in the prevalence rate of overweight (21–25 per cent) or obesity (5–6 per cent) over the past 10 years. There are specific trends emerging in different age groups, however. In youths aged 15–19 years, rates of overweight and obesity as measured by BMI are higher in males, but central obesity (measured by increased waist circumference) as a proportion of total adiposity appears to be increasing and is highest in girls (Garnett, Baur & Cowell, 2011).

**Dental health**

The dental health of Australia’s children and young people is measured by two main indicators. These are the proportion of children without tooth
decay at 6 and 12 years (55 per cent and 61 per cent, respectively, in 2007) and the mean number of decayed, missing or filled teeth (DMFT) at 12 years of age (0.96 in 2007) (AIHW, 2012). There is a recognised pattern of increased tooth decay among girls, thought to result from the earlier eruption of permanent teeth compared with boys. There are also small variations in rates of dental decay between states, with South Australia having the lowest mean DMFT score of 0.8.

Most Australian children will attend their first oral examination on school entry (5 years of age) and in 2010 some 78 per cent of children aged 5–14 years had visited a dentist at least once in the previous year (Chrisopoulos & Harford, 2013). Eighty per cent of Australian children (0–14 years) will grow up in areas with fluoridated water – a public health measure introduced to prevent tooth decay. The last Child Dental Health Survey, conducted between 2003 and 2004, showed that the majority of Australia’s 12-year-olds (58 per cent) had no evidence of tooth decay (AIHW, 2011a). This places the dental health of Australian 12-year-olds above the OECD average (DMFT score of 1.4), and ranks Australia eighth of 22 OECD countries using this measure for international comparison. More recent data suggest that little change has occurred. In 2009, the proportion of children with decay in their deciduous (first) teeth ranged from 42 per cent for 5-year-olds to 61 per cent for 9-year-olds, and the proportion of older children with decay present in their permanent (second) teeth ranged from 5 per cent for 6-year-olds to 58 per cent for 14-year-olds (Chrisopoulos & Harford, 2013).

Pain from dental or gum problems can interrupt normal eating, food choice and sleeping, and may impact on nutrition (weight), school attendance and social interactions between peers. The prevalence of dental and gum disease in Australian children and young people has decreased over time, but risk factors related to diet (such as sugary food and drinks)
and oral care (for example, tooth and gum hygiene) remain. Potential associations between dental health and future cardiovascular problems, lung disease and diabetes are an area of current research, but for children and young people, it is ongoing disparities in dental health across age and population groups that remain of greatest concern. During 2009–10, hospital separations related to potentially avoidable dental conditions were highest for Australian children aged 5–9 years (12,291 separations or 9.0 separations per 1000 children aged 5–9), followed by children aged 0–4 years (7,681 separations or 5.3 per 1000 children aged 0–4) (Chrisopoulos & Harford, 2013: 16).

Children living in regional and remote areas of Australia experience higher levels of tooth decay than those living in major cities (mean DMFT 1.2 and 0.9, respectively), a trend that may in part reflect differences in access to fluoridated water. The mean DMFT score of children living in the lowest socioeconomic regions in 2002–03 was almost 60 per cent higher (average of 1.1 teeth) than that of children from the highest socioeconomic areas (0.7), a trend evident across all states and territories of Australia. Indigenous children are at greatest risk of dental decay because of higher rates of socioeconomic disadvantage and remoteness. Nearly one-quarter of Aboriginal and Torres Strait Islander children (0–14 years) live in remote and very remote areas compared with only 2 per cent of other children of the same age (ABS, 2011a). Across a range of reports published between 2002 and 2004, Aboriginal and Torres Strait Islander children were reported to have a mean DMFT score of 1.4 (for South Australia) and 1.8 (for Victoria, Queensland, South Australia and the Northern Territory combined) compared with the mean DMFT of 1.0 for all Australian children. In 2008, some 30 per cent of Aboriginal and Torres Strait Islander children aged 0–14 years reported having teeth or gum problems (ABS, 2011a).
Social and emotional health

As we have already discussed, the teenage years mark a point of transition in morbidity and mortality patterns from those of childhood. Adolescents (13–18 years) are more likely to engage in risk-taking behaviours, but are also trying to adjust to normal individual variations in physical and emotional development. Mental health disorders account for nearly 50 per cent of the burden of disease among 15–24-year-olds in Australia (AIHW, 2008). Anxiety and depression diagnoses account for 17 per cent of the mental health disease burden for young men and 32 per cent of the disease burden for young women in this age range. In a report on the second only Australian Child and Adolescent Survey of Mental Health and Wellbeing (Lawrence et al., 2015) state that almost one in seven (13.9 per cent) of 4–17-year-olds were assessed as having mental disorders in the previous 12 months, equivalent to 560 000 Australian children and young people. Disturbingly, almost one-third of respondents with a disorder had two or more conditions at the same time, equating to 4.2 per cent of all 4–17-year-olds (Lawrence et al., 2015). Maintaining the mental health of Australia’s children and young people is a national health priority, but the process of defining indicators and conceptualising the scope of such a multidimensional and complex area is largely incomplete. There is evidence to suggest that children who are socially and emotionally confident and well adjusted will cope more successfully with the daily stressors and challenges of growing up (AIHW, 2011a). Conversely, children with low levels of social and emotional wellbeing are more likely to be at risk of behavioural and mental health problems, to have poor resilience and coping skills, and to experience a reduced engagement and performance at school (AIHW, 2011a). The causes of mental and behavioural disorders are complex, but can be related to any combination
of family, community, environmental, cultural, genetic or societal factors experienced by children and young people as they grow. Substance use may also be a contributing factor (Reavley et al., 2010). Young people with mental health disorders such as depression, anxiety, bipolar disorder (BD) and schizophrenia, and behavioural disorders such as Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD) and eating disorders, are more likely to experience poorer physical health, and reduced educational and employment attainment (AIHW, 2008).

In the absence of an agreed national indicator (and data) on the social and emotional wellbeing of Australia’s children and young people, measures such as hospitalisation rates for mental illness offer a poor estimate of prevalence. The extent to which children and young people receive treatment in the primary health care or private sector is not well understood. The hospitalisation rate for mental and behavioural disorders among children aged 5–12 years has not changed significantly since the late 1990s, and as we have previously noted, death by suicide is relatively rare in children under 15 years of age. In 2006–07, a total of 3900 children aged 5–12 years were hospitalised for mental and behavioural disorders, representing a rate of 178 children per 100 000 population (AIHW, 2011a).

In a 2013–14 household survey of parents and carers of 4–17-year-olds in the general population and 11–17-year-olds themselves, Lawrence and colleagues (2015) report that males were more likely than females to have experienced a mental disorder in the 12 months before the survey (16.3 per cent compared with 11.5 per cent). ADHD was the most commonly reported disorder (7.4 per cent), followed by anxiety disorders (6.9 per cent), major depressive disorder (2.8 per cent) and conduct disorder (2.1 per cent). The prevalence of mental and behavioural
problems rises in the adolescent population, with mood disorders such as depression and bipolar disorder more common in girls aged 15–19 years, and psychological development disorders such as language, learning and autistic spectrum disorders more common in males of this age. In 2008, 10 per cent of all 13–19-year-olds were hospitalised for some type of mental or behavioural problem (AIHW, 2008). This equates to 19 400 young Australians, or a prevalence of 973 per 100 000 of the 13–19-year-old Australian population. The number of days in hospital for each episode of care is represented as a bed day rate. The bed day rate in 2008 was 5800 per 100 000 (AIHW, 2008). While the bed day rate for schizophrenic and substance use-related hospitalisations fell between 1998–99 and 2006–07, there was a 20 per cent rise in hospitalisation for behavioural disorders and a 26 per cent rise in the mood disorder bed day rate among young women (AIHW, 2008). Mental health and behavioural disorders were 40 per cent more common in Aboriginal and Torres Strait Islander youth, and 33 per cent of suicide deaths between 2007 and 2011 were of young Aboriginal and Torres Strait Islander people (ABS, 2011b).

Encouragingly, the 2013–14 survey of children and young people’s mental health and wellbeing, conducted with children and young people in their homes, has shown an increase in children with mental health problems accessing mental health services (Lawrence et al., 2015), from one-third in the first survey in 1998 to two-thirds accessing health services in 2013.

**Reflection points 1.3**

- One-quarter of Australia’s children and young people are overweight or obese. The potential to intervene and prevent overweight or obesity is greatest in early childhood. Do you
Finally, it is important to acknowledge some other equally important, though perhaps less obvious, determinants of the mental health of Australia’s children and young people. These include health literacy, parental mental illness, school and peer stress and bullying, teenage pregnancy and birth, poverty, crime, and the misuse of drugs and alcohol, including a range of increasingly sophisticated and easily available psychedelic and hallucinogenic agents.

**Applying new knowledge to practice**

In this chapter, we have taken a closer look at historical influences on the health and wellbeing of the children and young people of Australia. We have also encouraged you to think about the wider context of family,
community, environmental, cultural and societal influences experienced by children and young people as they grow up in Australia. We hope you will read the following chapters with this broader vision in mind, and with a better understanding of the complex interactions that are possible between children, young people, their families and their environment.

Monitoring trends in health, estimating the effects of emerging infections or threats, and improving your knowledge of the many environmental or global factors that may impact on your care of families, children and young people provide a context for practice that will not come from your reading of any single text, research paper or systematic review. The Australian government provides a range of excellent resources to help you keep track of the health and wellbeing of children and young people living in Australia. These publications should become as much a part of your evidence base for practice as any emerging research (see Further Reading section below). But, as with all evidence, it is important to develop a critical lens for your reading of these frequently published reports. You need to remain aware of differences in units of measurement and denominators used, and think carefully about the demographic characteristics of the groups you are aiming to compare. You have already seen the difference in age ranges used to report on various health indicators, and how the lack of quality data from some regions and sectors of the Australian population impacts upon the integrity and accuracy of reported statistics. You may also have identified that significant inequalities within population groups can be masked or diluted by looking only at nationally aggregated population statistics and not at the specific sub-group or the region in which children and young people live.

As a paediatric nurse, you will find yourself in the privileged position of being invited to share the people, places and things that are most important to the children and young people for whom you care. Therefore,
while it may seem odd to begin a paediatric text with lessons from history, throughout this book we will make reference to the context in which Australia’s children and young people are growing up in Australia and within the global context: through their culture, home, family and friends. At times, this context will challenge you. The rosy social and economic picture Australia largely presents to the world will sometimes conflict with the impoverished or disturbing history of the young child for whom you are caring, the child or young person in detention or experiencing abuse, or the presentation of an angry young person struggling to make sense of themselves and their place in the world. Looking at ‘the bigger picture’ is something a health professional invited into the life of a child or young person must be able to do. And, as in all nursing work, the person in front of you – no matter how young or how old – is only ever one part of a much larger story.

**Summary**

- Australian government data collections are an extremely useful and important resource for recording and monitoring the demographic profile of children and young people living in Australia.

- Government data collections define a range of national indicators to describe the health and wellbeing of different age groups; they focus on a particular condition of interest and capture trends over periods of time. National health indicators are developed to be consistent with international indicators in order to facilitate benchmarking or comparisons.

- The health of Australia’s children and young people is good overall, but there are differences within and between
Learning activities

1.1 Search the World Health Organization Statistical Information System (WHOSIS) website at [www.who.int/whosis/en](http://www.who.int/whosis/en) (data are also published in May each year in the World Health Statistics Report). Here you can search among more than 70 health indicators collected for WHO member countries. Answer the following questions:

- Choose two indicators measuring an aspect of health or wellbeing in children or youth. Describe three or more major socioeconomic, geographic and cultural sub-populations. It is sometimes difficult to navigate the breadth and complexity of sub-population data to get a clear picture of what is happening to a particular group of Australian children and young people living in a particular place at any point in time.

- Overweight, obesity, dental health and social and emotional wellbeing (of which mental health is a component) are identified as possible emerging threats to the health and wellbeing of Australia’s children and young people.

- Current and past influences on the health and wellbeing of children and young people in Australia constitute a broad contextual framework of family, community, environmental, cultural, genetic and societal factors. It is fundamental to the holistic and person-centred approach of the paediatric nurse to consider the complex interactions between these influences when caring for children, young people and their families.
differences between the results of these indicators in developed and developing countries.

- What have been some major successes or failures in terms of health-care interventions for children and young people in these countries or regions (for example, immunisation)?

1.2 Find a reference or report that details major health trends for children and young people within your state or region. You may wish to limit your search to children or youth who have a particular disability or disease. Answer the following questions:

- How often is this report published?
- Who is the author (or authors)?
- What level of detail is reported (for example, death rates, specific diseases, age groups)?
- Does the report identify upward or downward trends in health statistics or health service delivery?

**Further reading**

The Australian government provides a range of excellent resources to help you keep track of the health and wellbeing of children and young people living in Australia. These are constantly updated and freely accessible through the following online resources:

- Australian Bureau of Statistics, Topics at Glance: [www.abs.gov.au/websitedbs/d3310114.nsf/home/topics+@+a+glance](http://www.abs.gov.au/websitedbs/d3310114.nsf/home/topics+@+a+glance)
In addition, there are a range of groups and organisations that regularly publish updates and reports about specific conditions or health priorities, including:

- **International Diabetes Federation**: [www.idf.org/diabetesatlas](http://www.idf.org/diabetesatlas)

**References**


International Diabetes Federation (IDF) 2013, *International Diabetes*


**Young person (or youth)** – A person aged 15–24 years

**Infancy** – The period from birth to 1 year of age

**Early childhood** – The period from 1 year to the fifth birthday

**Childhood** – The period from 5 years to the 13th birthday

**Adolescence** – The period from 13 to 18 years of age

**Rates** – Used to describe health trends over time – for example, a mortality (or death rate) is often presented as the number of deaths per 1000 population and is a ratio measure of the number of deaths from a particular cause (the numerator) presented as a proportion of all deaths from any cause (the denominator) over a defined period of time (usually one year)
Organisation for Economic Cooperation and Development (OECD) – A group of member countries that for the past 50 years have shared the mission of improving the economic and social wellbeing of people around the world. Starting with developed countries in Europe, the United States and Canada, there are now 35 member countries spanning the globe, including Australia and New Zealand. Various common indicators are collected across the OECD countries. It is common to see data for an individual country compared with the combined or average indicator for all OECD countries.

**Neonatal** – The period from birth to 28 days of age

**Comorbidity** – The presence of one or more additional disorders (or diseases) co-occurring with a primary disease or disorder

**Hospital separation rate** – An episode of care in a hospital – usually the period from admission to discharge (by transfer or death)

**Chronic condition** – Any ongoing physical or mental impairment that causes a functional limitation (or health burden), or necessitates the use of a service or care beyond that which is regarded as routine. The ABS (2009) defines a chronic condition as one that has lasted, or will last, for six months or more.

**Prevalence** – The term used to describe the existence of a condition or problem in any defined sector of the population at any given point in time

**Incidence** – The term used to describe the number of new cases of a condition or problem in any defined sector of the population at a given point in time

**Body Mass Index (BMI)** – Is calculated as follows: BMI = weight in kilograms divided by height in metres²
Child rights in Australia

Jennifer Fraser and Helen Stasa

**Learning objectives**

In this chapter you will:

- Be introduced to the concept of child rights, and in particular the rights of children and young people living in Australia
- Become familiar with the United Nations Declaration of the Rights of the Child
- Develop an understanding of how these rights translate into pediatric settings
- Develop an understanding of the purpose and intention of Australian policies that determine how, where and by whom children and young people will be cared for in the Australian health-care system
- Consider your professional priorities in relation to children’s rights and child-protection legislation
Introduction

This chapter builds on the information in Chapter 1 about the context of paediatric nursing in Australia. It is intended to provide a basis for understanding the ways in which children and young people’s rights are upheld in Australia, particularly within the health-care system. This extends to child protection, including nurses’ legal and moral responsibility to report child abuse and neglect.

As a nurse working with children, young people and their parents, you will be challenged to consider many important issues regarding your involvement with them as active participants in their health-care decisions. In your practice, you will explain which treatments or interventions are necessary, and decide whether the child or young person has the capacity to understand the importance and consequences of the choices that you make in collaboration with them and their family. Your assumptions about childhood and the role of parents will underpin the way in which you approach the child or young person and their family. These assumptions need to be evaluated critically and open to scrutiny and review, so you can provide the best possible care within a variety of contexts. This can sometimes be challenging, as there is a disparity of power in the relationships between the child or young person, you and the family, and this needs to be acknowledged and addressed.

The purpose of this chapter is to provide insight into the ways in which human rights, and particularly child rights, inform paediatric nursing policy and practice in Australia. The chapter explains how current Australian legislation attempts to ensure that child rights are protected within the health-care system. It begins by looking at the international agreements and covenants regarding the protection of child rights that have been endorsed by Australia, before moving on to examine the national
legislation. The second part of the chapter looks at some of the ethical challenges regarding child and family rights that you will have to consider as a paediatric nurse in Australia. In particular, we look at issues surrounding access to family, advocacy and consent to treatment of specific diseases in some situations. Further, the chapter provides a basis for understanding the way in which children and young people’s rights – including the right to be protected from all forms of violence and neglect – are upheld in Australia, particularly within the health and welfare systems.

**International legislation**

The United Nations (UN) Declaration of the Rights of the Child (UN, 1989a) and its guidelines provide a foundation for the way in which the dignity, wellbeing and human rights of children, young people and their families are respected globally. The Declaration sets out the standards of rights that are required to ensure that children and young people can live a minimally decent life.

Not only does legislation serve a protective function, ensuring the welfare status of the child, but children are also valued as individuals with human rights, and they are viewed as active in promoting and protecting their own rights, and not just passive agents. The Declaration of the Rights of the Child is based around four general principles: non-discrimination; life, survival and development; the best interests of the child; and respect for the child’s preferences and viewpoints. These underlie the Declaration’s specific Articles (see Table 2.1).

**Table 2.1 The four principles of the convention of the rights of the child**

| Non-discrimination | Best interests of the child |
Regarding health care, the Declaration explicitly states that the child ‘shall be entitled to grow and develop in health … [and] shall have the right to adequate nutrition, housing, recreation and medical services’ (UN, 1989b). The Convention was adopted by the United Nations in 1989, and was ratified in Australia in 1991 and New Zealand in 1993 (UN, 1989b).

Other relevant international human rights laws applicable to the health of children and young people in the Australian context include Article 3 of the Universal Declaration of Human Rights, which states that ‘everyone has a right to life’ (and the treatment required to sustain life). Additionally, Article 12(1) of the UN International Covenant on Economic, Social and Cultural Rights recognises ‘the right of everyone (of which children and young people are one group) to the enjoyment of the highest attainable standard of physical and mental health’. This Article is especially notable, as it makes specific reference to the fact that health encompasses both physical and mental aspects, rather than just focusing on the physical. Article 19 of the UN Convention on the Rights of the Child (UN, 1989a) expands upon this Covenant, and obligates state parties to take action and intervene to ‘protect the child from all forms of physical and mental violence, injury or abuse, neglect or negligent treatment’.
The UN Convention on the Rights of the Child emphasises that children have their own rights and entitlements, and that they need extra protection because of their youth (UN, 1989a). These fall into the four categories of rights: non-discrimination; life, survival and development; protection; and participation (UNICEF, 2004). The ‘rights to survival’ in the Convention not only include a guarantee to life, but also a guarantee of nutrition and health care at the highest level. Rights in this group include the right to survival, the right to have birth registration and nationality, the right to live with parents and the right to be taken care of. Among basic rights to food, shelter and clean water they include education and access to information about Child Rights (UNICEF, 2004).

The term ‘child protection’ is not limited to the prevention of physical and mental abuse; it includes the prevention and surmounting of disadvantageous conditions in children’s lives. According to the Convention, these rights include, but are not limited to, the right to be protected from all kinds of abuse and discrimination (UNICEF, 2004).

The right of the child or young person to make their own decisions about treatment or non-treatment are enshrined in Article 13(1), which provides:

The child shall have the right to freedom of expression; this right shall include the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers …

(UN, 1989a)

Clearly, at younger ages and in cases of cognitive impairment, a child may not have formed considered preferences regarding their medical care. In such situations, the health-care staff may need to rely on parents to provide information about the child’s treatment. However, in some situations the
parents’ preferences may conflict with what is thought to be in the best health-care interests of the child. In such circumstances, nursing staff have an important role to play in advocating to ensure that the child’s rights are protected, while also acknowledging the rights of parents to have their views heard.

**Reflection points 2.1**

Moral and ethical nursing practice is based on an ethos of lawful scope of practice and ethical standards. We acknowledge Article 13(1) of the UN Declaration of the Rights of the Child:

> The child shall have the right to freedom of expression; this right shall include the freedom to seek, receive and impart information and ideas of all kind: … (UN, 1989a)

- List specific groups of children and young people within Australian society that you believe need special safeguarding and care, as well as legal protection.
- Identify ways in which Australian paediatric nurses can apply children’s rights and health-care decision-making frameworks, ethical decision-making and informed consent for two of these highly vulnerable groups.

**Australian legislation**

**Implementation of international rights of the child**
The Australian legislation surrounding the protection of child rights is based on the international charters outlined above. Implementation of international rights of the child occurs through enacting child-specific treaties such as distinctive national policies, protocols and legislation. The Charter on the Rights of Children and Young People in Healthcare Services in Australia and the Consensus Standards for the Care of Children and Adolescents in Health Services (Hill et al., 2011) are two key documents that pertain specifically to the care of children and young people in the Australian health-care system. Both take a human rights-based approach to policy development.

Protecting children and their rights in the context of health care in Australian paediatric settings requires that the principle of family unity be recognised. This ensures that children and their families are not separated by hospital policy or discriminated against for any reason. Moreover, it ensures that they have access to appropriate services and service providers and that children’s agency is respected. One of the greatest challenges lies in developing and maintaining a model of care that is child focused and prioritises children’s inclusion. Children themselves must be at the forefront of stating how they wish to be cared for, and by whom (Coyne, Hallstrom & Soderback, 2016).

First, the Royal Australasian College of Physicians publishes Standards for the care of children and adolescents in health services (Royal Australasian College of Physicians, 2008). These articulate guidelines for high-quality health care that is safe and appropriate for the child or adolescent. The standards emphasise that the medical and psychosocial needs of children and young people differ greatly from those of adults, and state that it is important for health services to be designed to accommodate these diverse needs. The standards aim to ensure that the rights of children and young people are respected, that the facilities in
which they receive care are appropriate for their developmental age and that specially qualified staff are responsible for their care.

The second key Australian document related to the care of children and young people is a position statement entitled *Standards of practice for children and young people’s nurses*, published by the Australian College of Children and Young People’s Nurses (2016). This statement emphasises the engagement of all relevant stakeholders (such as the child or young person, their family, nursing and medical staff, allied health professionals and others) in the planning and delivery of care. It details the knowledge expected of nurses working with children and young people, and elucidates the expectations surrounding communication, family involvement and advocacy.

For nurses working in paediatric settings across Australia, these two documents are important references for the provision of high-quality care that, taken together with the international documents (such as the UN Declarations), provide a mechanism for attempting to ensure that the rights of children, young people and their families are protected by the health-care system.

**Reflection points 2.2**

- List ways in which nurses can protect children’s rights in hospital. Identify potential barriers to such protection and consider how these barriers may be addressed.

- Talk to a child or young person about a recent experience of illness. How did they feel about the care they received? Did they feel in control of the treatment decisions and that they were listened to by their parents/caregivers and health agency staff?
Practice implications

Having briefly outlined the key international and Australian national declarations regarding children, young people and families, and their applicability to the health-care setting, it is important to examine practical situations where, as a paediatric nurse, you may be required to make decisions that require a clear understanding of child rights and your associated responsibilities. In this section, we will examine some of the challenging situations that paediatric nurses may face regarding access to family, consent to treatment and advocacy for children at risk of abuse or neglect.

Access to family

Paediatric nursing care in Australia emphasises the importance of family-centred care. Family-centred care emerged as best practice in children’s health settings due to widespread interest in patient advocacy, with hospital visiting rights for parents one outcome of the advocacy movement. Within paediatric health-care settings, the term ‘family-centred care’ is used to describe an approach to nursing care that focuses on issues such the active involvement of parents in the care of the child; consideration of the child’s perspectives and views; and increasing children’s involvement in their treatment and decision-making about their treatment (Kuo et al., 2012).

As a paediatric nurse, you may need to rely on the child’s parents or guardians to make health-care decisions on the child’s behalf, particularly if the child is very young or has a condition that prevents them from exercising their autonomous choice. It is assumed that the parents will
make a decision based on the child’s best interests. It is therefore fundamental to consider models of family-centred care that emphasise training of parents to assume responsibility for care and decision-making, and that move towards truly collaborative relationships between children, their families and nurses.

The ways in which children’s choices can best be acknowledged within the Australian paediatric health-care system are supported by a broad literature devoted to the topic. Much of this relies on well-executed qualitative research that provides key insights into the ways in which nurses negotiate and coordinate the views and decisions of children and their parents. Unfortunately, it seems that there is still a long way to go before we can be confident that children are not marginalised in the health-care system, and therefore guarantee that their needs are not overlooked.

Using a critical ethnography to study children’s in-patient hospital experiences, Livesley and Long (2013) conclude that children have little say in how they are cared for. Children without an adult advocate, such as a parent, in attendance are least likely to be able to negotiate how they are treated in hospital. Children in the study were drawn from a cohort of patients in a nephro-urology ward in the north of England. They typically resorted to attention-seeking behaviours to try to get what they needed from nurses. Children who were less capable of asserting themselves were observed to receive minimal nursing care. What we can see is that some of the defiant and oppositional behaviour that we witness in paediatric settings may in fact be a way for children to demand better or more appropriate care according to their needs. Future research is needed to guide our understanding of how children communicate their need for care and attention, and how nurses can best interpret hospitalised children’s behaviour. We will look at this aspect of caring for children in paediatric settings in more depth in Chapter 7.
In summary, using a developmental approach, children become increasingly involved in their own health-care decisions as health literacy develops. In line with a child rights perspective, children with the necessary capacity and capability should be involved despite their age. That is, rather than suggesting a particular age at which decision-making is encouraged, children are deemed to be capable of making their own decisions and ought to be involved and consulted. In Australia, children must assent (voluntarily agree) to treatment before legal autonomy; however, it is their parents who must give formal consent.

**Australian age-of-majority legislation**

For most Australian jurisdictions, 18 years is the age of legal autonomy, when the person can give consent for treatment without parental approval. This does vary, however. The age for making medical decisions in New South Wales is 14 (Minors (Property and Contracts) Act 1970 (NSW), s 49) and in South Australia a person 16 years of age or older may make decisions about their own medical treatment (Consent to Medical Treatment and Palliative Care Act 1995, s 6) (see Box 2.1).

**Box 2.1  Age-of-majority legislation in Australia**

**Consent to medical treatment**

The age of consent for medical treatment differs across jurisdictions; for example, in Western Australia the age of consent remains at 18 years (the general age of majority in Australia); however, in New South Wales and South Australia, the age of consent for making decisions regarding medical treatment has been amended by legislation to 14 and 16 years, respectively.
Generally, treatment provided to children below the age of 16 requires the consent of their parents or guardians. Parents may only consent to treatment that is in the best interests of the child.

In all jurisdictions, the consent of the child alone may be sufficient in circumstances where the child has ‘sufficient understanding and intelligence to enable him or her to understand fully what is proposed’ (Gillick test, from the case Gillick v West Norfolk AHA (1986); see also Harrison, 1992). In South Australia, this test has been modified by statute to be: where the child consents, and (1) the medical practitioner is satisfied that the child is capable of understanding the nature, consequences, and risks of the treatment, and that the treatment is in the best interests of the child’s health and wellbeing; and (2) that this opinion of the medical practitioner is supported by the written opinion of another medical practitioner who has also examined the child.

A parent may not consent to certain treatments of children. Where a treatment involves major, invasive and irreversible surgery that is not for the purpose of curing a malfunction or disease – for example, sterilisation or gender reassignment – neither a child nor a parent may consent, and it is necessary to obtain the consent of both the court exercising jurisdiction under the Family Law Act 1975, or authorised by legislation to consent, and the parents (Gillick test; see Harrison, 1992).

Children generally may only participate in medical research with the consent of both the child and the parent in circumstances where the research is not contrary to the best interests of the child (Australian Government NHRC, 2001).

As children make the transition to adulthood, they develop the ability to be responsible for their actions. The parents’ responsibility for the child gives way to the child’s autonomy. In the paediatric hospital setting, the adolescent may make a difficult transition into adult care – especially if they have had multiple hospital admissions and developed close relationships with their caregivers.

One particularly pertinent issue that arises with the transition to adult care concerns the competence of the adolescent to make informed, rational decisions about their care and treatment. Regarding consent to medical treatment, the term ‘Gillick principle’ must be understood. A House of Lords ruling in *Gillick v West Norfolk Area Health Authority* (1986) states that if a child under the age of 16 can demonstrate sufficient understanding and intelligence (whether through words or actions) to understand fully the treatment proposed, they can give their consent to treatment in the absence of parental consent (Woolley, 2005: 717). This ruling only applies to medical treatment that has clear potential for direct benefit to the health of the child. It is also important to remember that the Gillick principle applies only to a decision to receive treatment: it does not apply in cases of refusing treatment. Indeed, as the New South Wales Law Reform Commission has stated, in some instances it may be possible for the courts to override a young person’s decision to refuse treatment (for instance, if this decision is made on religious or spiritual grounds that prohibit receiving particular forms of health-care treatment) if it is believed that it is in the young person’s best interests to receive the care (NSWLRC, 2008).

In Australia, the law is clear that a child can give legally informed and effective consent to medical treatment using a Gillick assessment, although it is not obligatory. Australian law still has some way to go in upholding children’s rights to medical treatment without parental consent.
The next section of this chapter looks more closely at the relationship between children and their parents, and presents the responsibilities of health-care professionals, including registered nurses, in protecting children from harm.

Priorities in relation to children’s rights and child-protection legislation

Child abuse and neglect refer to a wide range of behaviours. These include acts of commission related to physical, sexual, emotional or psychological harm to children, as well as acts of omission related to physical and emotional neglect. The categories of neglect, physical injury, sexual abuse and emotional abuse are widely used for the purposes of child abuse notification, substantiation of child abuse cases and prosecution. Notwithstanding this, there are variations between Australian states and territories regarding what constitutes child abuse and neglect. Not only do the definitions vary; there are also some differences in what nurses are mandated to report to the child-protection authorities. This is because each state and territory in Australia has separate legislation aimed at protecting children from abuse and neglect. Thus child abuse and neglect notifications are substantiated in accordance with legislation in each jurisdiction. Australia has an estimated child abuse and neglect incidence rate of almost eight per 1000 children in the age group from birth to 16 years (AIHW, 2016).

Being able to recognise the abuse and neglect of children is the most important first step in being able to provide early intervention to reduce the harm these actions can cause. Prevention is even better, so once a child and family are recognised as needing extra support there is a chance that
risk factors for child abuse and neglect can be reduced. At the same time, it must be recognised that the parent, child and environment transact over time. The scope of child abuse and neglect becomes even more extensive as research reveals the impact of maltreatment on children’s development. These issues then further impact on other parts of the child’s personality and behaviour in a dangerous spiral.

Registered nurses in Australia have a significant role in recognising, reporting and responding to child abuse and neglect. Mandatory reporting of known and suspected child abuse and neglect is well established in all states and territories, and guidelines are available to make reporting efficient and effective. Registered nurses identify, evaluate and document injuries and manage the protection of children in their care to intervene early and prevent further harm. Collaboration with law-enforcement bodies, social service agencies, advocacy organisations where they exist and the criminal justice system is essential to provide a network of support.

The intent of legislation that mandates reporting to child-protection authorities is to promote early intervention and prevent further violence and abuse. There are no penalties that can be applied to nurses who, in the course of their duty, make a report in good faith. Unfortunately, the penalty for children who are not recognised or reported can be further abuse or neglect. Almost one-third of infants who presented to one of four hospitals with head injuries sustained through acts of child abuse in a North American study of 232 infants could have been identified as being at risk prior to the admission for abusive head trauma (Letson et al., 2016). Had these children’s vulnerabilities been recognised in earlier admissions to the hospital or health-care agency, the chances for prevention of ongoing disability or even death may have increased.
The responsibility to report child maltreatment

It must be understood that registered nurses in Australia are mandated by state and territory laws to report to a designated authority knowledge or suspicion of a child who is experiencing, has experienced or is likely to experience significant harm. Legislation in some jurisdictions is limited to type of abuse and significant harm. Nevertheless, where this is the case – that is, where there is not a legislative duty to report certain forms of abuse – occupational and health service policy requirements exist. Yet, despite these legal and policy obligations, only 10.6 per cent of all reports to statutory child-protection authorities came from health professionals, compared with 21.8 per cent from police and 16.7 per cent from schools in the latest report (AIHW, 2016: 73). This also occurs in Canada, where ‘school personnel, police and social workers report more child abuse and neglect than health-care professionals do’ (Tonmyr et al., 2009). There is growing research interest in determining the underlying reasons for this, given nurses’ exposure to children and families across a range of settings. It is important to tease out whether these factors are related to nurses’ skills, knowledge and attitudes, or that there are more systematic workplace issues creating barriers to reporting. Do nurses in Australia view child protection as part of their role to the same extent as doctors, police, social workers and others? Are nurses conflicted about their role as advocates for families and children, versus that as advocates for their profession or the health-care agency? These and other questions have been studied in recent Australian research.

In a study of Queensland nurses, 21.1 per cent of nurses surveyed had never reported maltreatment and 26.6 per cent who had made notifications had failed to report on at least one occasion (Fraser et al., 2010), despite being aware of the legal responsibility to do so. Nurses are not alone in
their reluctance to report. Even though 97 per cent of general practitioners surveyed in Queensland were aware of the responsibility to report child abuse and neglect, 26 per cent had decided at least once not to do so (Schweitzer et al., 2006). Alarmingly, one of the reasons they gave for not reporting was that they considered the abuse to be a one-off event and viewed further harm to the child as being very unlikely.

Compliance with legislation to report child abuse and neglect is compromised by a number of individual and contextual factors. At the level of the individual – let’s call this a proximal factor – is the ability to recognise past, current and future abuse and neglect. Knowledge of child abuse and neglect recognition is variable, and depends on whether the topic is covered in professional development courses or staff training. There is sufficient evidence to indicate the relationship of injury presentations and physical and sexual abuse, for example, but staff need to have this knowledge. Certain physical injury presentations are more likely to have resulted from maltreatment. All fractures in a pre-ambulatory child should be treated as suspicious. The child-protection registrar, where available, or a senior medical officer must be notified immediately of any such presentation. Fractures of the femur (Leventhal et al., 2011), rib fractures and those caused by twisting forces, skull fractures or a combination of a skull and long bone fracture are associated with abuse (Bandyopadhyay & Yen, 2002). Head injury is the most common cause of fatal inflicted injury in children (King, Kiesel & Simon, 2006). Unfortunately, it is seen in those under 2 years of age due to the increased vulnerability of infants (Berkowitz, 1995; DiScala et al., 2000).

Acceleration–deceleration injuries indicate that the infant has been shaken, and a diagnosis of Shaken baby syndrome will be investigated: ‘When considering the causes of injury, it is not enough to undertake a physical assessment of injury and risk alone. Shaken baby syndrome often
presents with subdural or subarachnoid bleeding, cerebral oedema, long bone and/or rib fractures, retinal bleeding and little or no cranio-facial trauma’ (Cadzow & Armstrong, 2000; Kairys et al., 2001; Reece & Sege, 2000). Careful documentation is necessary, as the case may not be clear and symptoms can be diverse, such as abdominal pain and loss of consciousness (Jenny et al., 1999; Kairys et al., 2001; Keenan et al., 2004). Detailed recording of the history – that is, the parents’ story – is necessary every time it is told. Inconsistencies across time and between the parents’ recall are suspicious (Scott, 2013; Scott, Higgins & Franklin, 2012).

Cases of neglect and emotional abuse have emerged as the most problematic forms of child maltreatment in Australia (AIHW, 2016: 22). While progress has been made in identifying and reducing both child physical and sexual abuse, substantiated notifications of neglect and emotional abuse are increasing. It is crucial to be able to recognise the risks of abuse and neglect, and to report suspicion. In all cases of reporting, it is not the nurse’s individual responsibility to substantiate the suspicion, but rather to detail the seriousness of the harm or potential harm to the child.

Case study 2.1

A nurse’s dilemma
Chung is an 8-year-old boy born to Chinese parents in Australia. He is often struck by his father with a rod, sometimes for only minor discretions such as being late home from school. Over a period of time, Chung starts to feel sad a lot and loses confidence in himself. He subsequently suffers high levels of anxiety, and withdraws from his friends, which leads him to distance himself from them. His friends do not understand why this is happening
and start to tease him. Chung responds to this with physical violence, which gets him in trouble with the teacher at his school and consequently into more trouble with his father.

Wang Li (Lianne) is a registered nurse working in the emergency department of a busy children’s hospital in metropolitan Sydney. Wang Li has a legal obligation to report child abuse and neglect to the child-protection authorities, depending on the severity of harm to the child. If the abuse or neglect is deemed to be serious, then she is compelled by legislation and of course hospital policy to make a report. Chung has presented to the hospital where she is working. He is anxious and struggling to breathe. He presents regularly at the hospital, always accompanied by his mother. He has asthma and a strong history of eczema. His mother says both conditions are really playing up at the moment and that Chung is very anxious. He has been doing exams at school and is worried he has not done well.

Using their shared Mandarin language, Wang Li asks Chung’s mother whether she knows what might be upsetting him. In Mandarin, Chung’s mother discloses the extent to which her husband beats young Chung and makes him spend hours doing homework, even when he is too tired to concentrate. She wants him to stop but is afraid of his reaction if she says anything. She appeals to Wang Li not to mention it to anyone, as she is so ashamed and believes that no other Chinese parent living in Australia would treat their child in this way.

Wang Li is aware of her legal obligation to report the abuse, which she understands to be causing serious harm to Chung’s wellbeing. However, she is uncertain about whether reporting the concern would be in the best interests of this family. She too was
brought up to believe that if you spare the rod you spoil the child – that is, that harsh punishment of children is necessary for their growth and development. Her father was very stern but loving towards her. She has developed a trusting relationship with Chung’s mother and feels that she would betray her trust by making a report. Wang Li is not sure whether she can discuss the report with colleagues and whether her identity would be protected.

The multidisciplinary response to child protection
Concerns expressed by Wang Li in this scenario are known to be barriers to reporting. Approximately one-fifth of the population of nurses surveyed in Australia and overseas (Feng & Levine, 2005; Fraser et al., 2006; Lee, Fraser & Chou, 2007) admit to having not reported their suspicion of abuse or neglect, even when mandated to do so.

Case study resolution
The registered nurse is mandated to report the abuse to the appropriate child-protection agency. In most jurisdictions in Australia, this is enabled by the fact that the nurse can confer with other health professionals and follow a protocol. The registered nurse in this case is mandated to report any child abuse and neglect she identifies or suspects in the course of her professional work. Some jurisdictions may have legislation that compels the nurse to report even if it is not part of the professional role. Details of the current legislation for the jurisdiction within which you are working should be well understood and opportunities for training taken.
Wang Li’s identity in this case would be protected by Australian law, and she would not be liable for making a report that could not be substantiated if she makes the report in good faith. Depending on the jurisdiction, if she fails to report a penalty may be incurred. It is important to note that to make a report in Australia, the registered nurse does not have to be able to substantiate the abuse or neglect. She makes a report so that an investigation can be commenced. A Chinese family was presented in the case study to highlight some of the cultural considerations nurses may need to make when reporting. The case study highlights that child abuse and neglect occur across cultures and religions.

Apart from the legal responsibility, the ethical and moral obligation to report abuse to the appropriate child-protection authority should actually enhance the nurse–family relationship because it should allow for the provision of much-needed assistance to families struggling to provide good parenting for their children. Unfortunately, we know that a number of health professionals, doctors and nurses do not share this optimism, and a critical debate remains about further expansion of mandatory reporting laws for child abuse and neglect (Mathews, 2012).

Summary

- This chapter introduced the concept of child rights within the scope of paediatric nursing, and particularly the rights of children and young people experiencing paediatric nursing care in Australia.
• The relationship between the UN Declaration of the Rights of the Child, to which Australia is a signatory, and policies on the quality of health care received by children and young people in Australia, were explored.

• The chapter explained the way in which child rights are integrated into Australian policies that determine how children and young people will be cared for in Australian paediatric health-care settings and outlined the mandatory reporting legislation that promotes nurses as advocates for children.

• It is anticipated that you will consider your professional priorities in relation to children’s rights and child-protection legislation.

Learning activities

2.1 Describe standards of nursing practice that relate to the care of children in Australia.

2.2 Describe standards of nursing practice related to the care of young people in Australia.

2.3 Discuss professional boundaries in the therapeutic relationship when providing nursing care for children and families.

2.4 Analyse nursing roles and responsibilities with regard to protecting children from harm.

2.5 Do you think it should be the responsibility of nurses to report child abuse and neglect? Discuss.

Further reading

The relationship between the UN Declaration of the Rights of the Child, to which Australia is a signatory, and policies on the quality of health care received by children and young people in Australia, were explored.

The chapter explained the way in which child rights are integrated into Australian policies that determine how children and young people will be cared for in Australian paediatric health-care settings and outlined the mandatory reporting legislation that promotes nurses as advocates for children.

It is anticipated that you will consider your professional priorities in relation to children’s rights and child-protection legislation.
• For more detailed information about child maltreatment and the obligation you have as a health professional to recognise and respond to known or suspected cases, access the excellent training materials provided by the International Society for the Prevention of Child Abuse and Neglect at www.ispcan.org/?page=Training_Materials.

• For further information about human rights and child rights, go to www.unicef.org/crc/index_30160.html.

• The International Council of Nurses (ICN) publishes position statements relating to nursing practice. The following links take you to the key international statements on nursing ethics and position statements relating to child rights (you will need to be a member for access):
  
  
  
  

References

Australian College of Children and Young People’s Nurses (ACCYPN) 2016, Standards of practice for children and young people’s nurses, ACCYPN, Brisbane.


*Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL).


**Participation** – A key tenet of children’s rights is their right to freely express their views and actively participate in making decisions about all matters, including health and education.

**Child protection** – Australian children are legally protected from harm through a number of Acts aimed at shielding them from abuse and neglect in all their forms.

**Child rights** – Civil, political, economic, social and cultural human rights are afforded to Australian children with consideration for their vulnerability and potential for exploitation as they grow and develop. These rights are protected in Australian law.
Family and community

Ibi Patane and Elizabeth Forster

Learning objectives

In this chapter you will:

- Come to understand that the focus of paediatric nursing care includes both the child or young person and their family
- Explore contemporary family characteristics relevant to paediatric nursing
- Explore models of paediatric nursing care that promote family partnership and involvement
- Gain an understanding of family assessment and apply family assessment models to a case
- Gain an understanding of important considerations when conducting family assessment
Introduction

In paediatric nursing, families are central to the care of children – in fact, the patient is considered to be both the child and their whole family. In this chapter, you will explore what it means to be a family, learn about the models of paediatric nursing care that emphasise a focus on both the child and their family and discover the frameworks that can be used to assess families in paediatric nursing practice. You will also be invited to consider some of the tensions or challenges experienced by paediatric nurses during care for children and families.

Families in contemporary Australian society

Families in Australia today are diverse in terms of their structure, as well as their membership and functions. Because of this, the concept of ‘family’ is quite challenging to define. It is perhaps useful to think of McCaffery’s (1968) reference to pain as being ‘whatever the patient says it is’ and consider families to be defined by their members; even though members of a family may have no blood relationship, they may consider themselves to be a family.

Contemporary Australian families may be:

- experiencing or adjusting to marital breakdown
- lone-parent households
- blended or step-families
- same-sex parents with children
- migrant and refugee families
The nature of families has an impact on child health and wellbeing, as families are instrumental in ensuring that children’s needs are met from birth through to adolescence and beyond. Families are the social connection between their members and the outside world, and are responsible for role modelling and socialisation. Exposure to a negative or disruptive family environment during early childhood can have a lasting impact on a child’s social, cognitive and emotional development. According to Munns and Shields (2013), these effects may be transferred on to the next generation.

A variety of models recognise and promote family involvement in a child’s care, and this chapter will look at two of these models: the Family Partnership Model and family-centred care.

**The Family Partnership Model**

The Family Partnership Model was developed in the United Kingdom by the Centre for Parent and Child Support (Davis, Day & Bidmead, 2002). Its original focus was to support early intervention in child mental health. It has been used primarily within community child health practice, both within Australia and abroad. The principles, however, are relevant to any context where nurses are caring for children and their families. The Family Partnership Model aims to assist parents and children to:

- identify and build upon their strengths
- clarify and manage problems
• develop resilience and the ability to anticipate problems
• enhance/improve child development and wellbeing
• harness social support (Davis et al., 2007).

The model also aims to foster community development, services development and improvement.

The Family Partnership Model also outlines a variety of helper qualities, including respect, genuineness, empathy, humility, quiet enthusiasm, personal strength and integrity, as well as intellectual and emotional attunement (Davis et al., 2007). In addition, helpers use a variety of communication, problem-solving and negotiation skills to establish an effective partnership with parents.

Child health nurses who have trained within the Family Partnership Model and used it in practice have described a shift in their practice so that they are moving away from telling parents what to do to solve a problem towards exploring and facilitating parent needs. This involves asking parents what the nurse could do to assist and what parents want from the nurse, which places greater emphasis on parent control during interactions (Fowler et al., 2012). Nurses also develop skills within the foundation of a trusting relationship to challenge negative parent constructions in order to ‘develop different, more positive ways of thinking about issues’ (Fowler et al., 2012).

**Family-centred care**

‘Family-centred care’ is a phrase that has been defined and conceptualised in many ways. It is seen as a paradigm, a philosophy, a model of care and a practice theory (Mikkelsen & Frederiksen, 2011). For the purposes of
this chapter, it will be seen as a model of paediatric nursing care, and defined as

a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, where all the family members are recognised as care recipients and where family involvement is considered to be central to a child’s care (Shields, Pratt & Hunter, 2006: 1318).

Family-centred care is the most frequently used model to enhance the involvement of parents in their child’s health care. As seen in the above definitions, the whole family is the focus of care (Coyne, 2013). Yet, despite strong agreement among clinicians that this model has benefits for both children and their families (Coyne, 2013; Shields, 2010), there is limited evidence that it impacts upon outcomes (Kuo et al., 2012; Shields et al., 2012).

Family-centred care has its challenges, and despite its popularity, its definition remains unclear in many settings. Its actual application in clinical practice has also been scrutinised (Kuo et al., 2012). This may be because it contrasts with more traditional approaches to care, where responsibility and control rest with health-care professionals rather than parents (Kuo et al., 2012).

Some of the problems with its application in clinical settings are thought to be due to inadequacies in knowledge and skills, the increasing stress clinicians encounter in fulfilling their roles, problems with negotiation processes, power struggles between clinicians and parents, and insufficient organisational supports for its implementation (Coyne, 2013). As reported by nurses, communication with families and the negotiation of care can sometimes be challenging, and this is another reason for the
problems that have emerged with the implementation of family-centred care (Coyne, 2013). Some clinicians may not like to relinquish control of certain aspects of care to parents, and this undermines the notion of partnership that is central to family-centred care (Coyne et al., 2011).

**Reflection points 3.1**

- Families may be quite diverse in terms of their composition and structure. In Australia, contemporary families may be adjusting to marital breakdown, be sole-parent, blended or same-sex parent families, be culturally and linguistically diverse, be experiencing stressors associated with domestic violence, have migration or refugee concerns, or be coping with a family member’s disability, injury or illness.

- The Family Partnership Model can be used by nurses to enhance family strengths, problem-solving and resilience in order to optimise child development and wellbeing. It necessitates a shift away from the traditional nurse-controlled way of approaching care towards a style of care that explores and facilitates parents’ preferences and needs.

- Family-centred care is a model of paediatric nursing care where the child and the whole family are the focus of care; it is underpinned by family involvement, participation and partnership in the child’s care. Nurses caring for children continually negotiate with and empower parents to be involved in their child’s care.

- Family assessment is integral to planning and providing family-centred care. All families have strengths that will assist them to
Family assessment

In order to provide a high standard of care to children and families, we need to understand the roles, functions, strengths and limitations, stressors and coping strategies in which families engage and that they experience. Family assessment is a way to ascertain information about each family and to explore how a health problem experienced by one of its members impacts the family.

A variety of family assessment models exist and are used by paediatric nurses – for example, the Calgary Family Assessment Model and the Friedman Family Assessment tool. Most assessment models have a few elements of assessment in common, which usually include:

- a family genogram/ecomap or visual representation of the family structure
- assessment of the developmental stage of the family
- assessment of roles and functions within the family
- assessment of stressors experienced by the family
- assessment of coping strategies used by the family.

We will now discuss these elements of family assessment so you will have a good understanding of these in your paediatric nursing practice.

Family genogram/ecomap
The structure of the family is important to understand when considering family assessment. This can often be complex to explain, and genograms are a diagrammatic way to map the family structure and each person’s relationship within the family unit in relation to the patient (Wright & Leahey, 2013).

Figure 3.1 shows a simple genogram of a typical family, with both partners having remarried. The square shapes symbolise males and the circles females, with lines indicating relationships and crosses through lines indicating relationships that have ended (such as by death or divorce). The children are mapped and connected to their parents. The patient who is the focus of the genogram, Milly, is highlighted.

![Genogram Diagram](image)

**Figure 3.1** An example of a genogram

Further, the nurse can explore the family’s interactions within its community and map these external interactions (Holtslander, Solar & Smith, 2013). These diagrams are called ecomaps, and can be useful when assisting families to draw on resources to assist them by identifying their current supports. The family is central in the ecomap, and the support systems are mapped, with the number and boldness of the connecting lines indicating the strength of the relationship and support (Neves, Cabral & da Silveira, 2013). In the ecomap in **Figure 3.2**, the couple report moderate...
support from each other, and only one strong source of support from their community. One potential source of support is not linked at all; this could be family members who may be geographically distant.

Figure 3.2 An example of an ecomap

More recently, emotion mapping has been used in some studies to represent family member feelings and interpersonal relating within couple and family relationships and set this mapping against the background of the couple or family home environment (Gabb & Singh, 2015a, 2015b). Within this approach, emoticon symbols are used to depict the emotions experienced by family members in relation to other members. For example, each family member is given a sticker colour, and emoticons such as laughter, happiness, indifference, sadness, upset, grumpiness/anger and love/affection are used to depict the feelings experienced by family members in different locations within the family home (Gabb & Singh, 2015a). This strategy can be also used by children to gain an insight into their perceptions regarding their own and family member feelings.

Family development

Family development can be understood from a variety of standpoints. Family developmental theory and family life-cycle stages (McGoldrick, Carter & Garcia-Preto, 2011) are two ways of thinking about family development. Essentially, it is thought that family roles and tasks are
influenced by the stage of the family. For example, a family with teenagers is likely to have different roles and a different focus from a beginning family experiencing the birth of their first child. Understanding the stages of development experienced by families over a lifetime can give paediatric nurses an understanding of significant events, challenges, roles and tasks that may occur during these times.

McGoldrick, Carter & Garcia-Preto’s (2011) family life-cycle stages include:

- leaving home: single young adults
- the joining of family through marriage: the new couple
- families with young children
- families with adolescents
- launching children and moving on
- families in later life.

One of the early criticisms of this model was that it was based on understandings of middle-class North American families, and therefore did not consider the dynamic and diverse nature of the families that exist in society today. Since it was first developed, a variety of other family life-cycle models have been developed and introduced, including family life-cycles for divorced and remarried, professional and low-income, adoptive, and homosexual, bisexual and transgendered families (Wright & Leahey, 2013). The development of these family life-cycles reflects the limitations of a single model in terms of understanding family development across the lifespan, and acknowledges that families are diverse and constantly changing.
At each stage during the life-cycle, families have particular tasks to fulfil, and attachments between members form and change. **Table 3.1** summarises some of the tasks and attachments that may be significant at each stage.

**Table 3.1 Family life-cycle stage tasks and attachments**

<table>
<thead>
<tr>
<th>Family life-cycle stage</th>
<th>Tasks</th>
<th>Attachments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaving home: single young adults</td>
<td>Differentiation of self in relation to family of origin</td>
<td>Attachment between young adults and their respective parents</td>
</tr>
<tr>
<td></td>
<td>Development of intimate peer relationships</td>
<td>Attachment between parents</td>
</tr>
<tr>
<td></td>
<td>Establishment of self in relation to work and financial independence</td>
<td></td>
</tr>
<tr>
<td>The joining of family through marriage: the new couple</td>
<td>Establishment of couple identity</td>
<td>Attachments between spouses</td>
</tr>
<tr>
<td></td>
<td>Realignment of relationships with extended families to include spouse</td>
<td>Attachments between each spouse and their respective family of origin</td>
</tr>
<tr>
<td></td>
<td>Decisions about parenthood</td>
<td>Attachments with outside interests</td>
</tr>
<tr>
<td>Families with young children</td>
<td>Adjusting the marital system to make space for the child</td>
<td>Attachments between parents</td>
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</tr>
<tr>
<td></td>
<td>Joining in childcare, financial and household tasks</td>
<td>Attachments between parents and children</td>
</tr>
<tr>
<td></td>
<td>Realignement of relationships with extended family to include parenting and grandparenting roles</td>
<td>Attachments between siblings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Families with adolescents</th>
<th>Adjusting parent–child relationships to allow adolescents to move in/out of the family system</th>
<th>Possible decrease in parental attachment for adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mid-life marital and career issues</td>
<td>Adolescent attachment with peer group</td>
</tr>
<tr>
<td></td>
<td>Beginning shift towards joint caring for the older generation</td>
<td>Attachment between family members</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Launching children and moving on</th>
<th>Renegotiation of marital dyad</th>
<th>Attachments between family members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Development of adult-to-adult relationships between parents and grown children</td>
<td>Attachments to outside interests</td>
</tr>
</tbody>
</table>
Realignment of relationships to include in-laws and grown children

Dealing with disabilities and death of grandparents

<table>
<thead>
<tr>
<th>Families in later life</th>
<th>Maintaining own or couple functioning and interest in the face of physiological decline: exploration of new familial and social role options</th>
<th>Interdependence with the next generation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Making room for the wisdom and experience of seniors</td>
<td>Intergenerational attachments, especially between daughters and parents</td>
</tr>
<tr>
<td></td>
<td>Dealing with loss of spouse, siblings, peers and preparation for death</td>
<td></td>
</tr>
</tbody>
</table>

Source: Adapted from McGoldrick, Carter & Garcia-Preto (2011); Wright & Leahey (2013).

Family roles and functions
Families exist to meet the needs of the individuals within a family, to expand through reproductive functions and to ensure socialisation of new family members. The main functions of the family can be summarised as follows:

- affective function – meeting psychological needs
- social function – meeting social needs and ensuring children become productive within their social group
- reproductive function
- economic function
- health-care function (Friedman, Bowden & Jones, 2003).

However, over time, traditional roles within the family have changed – for example, more families today combine raising children with work commitments as mothers have increased involvement in the workforce compared with previous decades (Cooklin et al., 2016). This change has impacted on mother and father roles and expectations within the family. It is important to acknowledge the diverse nature of contemporary families, which may vary in terms of their structure, roles and functioning.

**Stressors**

Contemporary families cope with many day-to-day stressors. As already mentioned, a common stressor for modern families is balancing working life with the constant demands of raising children. However, there are more profound stressors that bring about change within a family unit. These can have a significant impact on a child’s development, and a family’s resilience, strength and capacity to cope are important protective factors.
Such stressors can be major life events, such as a death within the family or parental conflict, or they may be ongoing stressors, such as chronic disease and low socioeconomic status. High family stress correlates with a lower satisfaction with life in adolescents (Chappel, Suldo & Ogg, 2014). It is also known that accumulated stressors add to the burden. If children and their families do not adapt well to stress, this can lead to academic, interpersonal and emotional difficulties later in life (Valdez, Chavez & Woulfe, 2013). Therefore, it is important for nurses to guide families towards positive coping strategies.

Coping strategies

Each family has its own culture, and will thus develop its own coping skills. When faced with stressors such as the experience of a severely or chronically ill child, family members may react in different ways. Coping is defined by Friedman and colleagues (2003: 466) as ‘problem solving efforts by an individual’. These can be positive or negative. Coping was originally conceptualised as being either emotion-focused coping or problem-focused coping, with the first involving the regulation of negative emotions using strategies such as distancing, seeking emotional support or avoidance, and the second type involving a planned approach to addressing the problem using information-seeking and decision-making (Folkman, 2013). More recently, a third type of coping, known as meaning-focused coping, has been proposed; it includes drawing upon inner beliefs and values, revising goals, focusing on the strengths obtained through experience and reorganising priorities (Folkman, 2013).

Families have strengths that will enable them to develop coping skills when faced with stress. These are listed by Feeley and Gottlieb (2000) as their individual family traits, assets and capabilities, together with qualities
such as motivation. Understanding the context of the family and the way each member of the family is situated in that family group (Jokinen, 2004) may assist you to identify and justify the coping strategies employed by that family and provide guidance towards positive coping strategies.

Gender is an important influence when it comes to coping, and mothers and fathers may have quite different coping styles (Brown et al., 2013). For example, in a study of parents whose child had been diagnosed with developmental delay, it was found that mothers tended to engage in emotion-focused coping whereas fathers used a more cognitive and logical style of coping (Barak-Levy & Atzaba-Poria, 2013).

Families cope with stress in many ways. Table 3.2 summarises some of the coping strategies that can be seen in families experiencing stressful situations.

**Table 3.2 Family stress, coping and adaptation**

<table>
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<tr>
<th>Developing enhanced relationships within the family:</th>
<th>Family social supports:</th>
<th>Denial of family problems and reactive behaviours, such as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• relying on each other</td>
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<td>• emotional exploitation</td>
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<tr>
<td>• strengthening cohesion</td>
<td>• seeking advice from relatives</td>
<td>• blaming (scapegoating)</td>
</tr>
<tr>
<td>• developing flexible roles</td>
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</tbody>
</table>
Cognitive strategies
- being as ‘normal’ as possible
- passive acceptance
- ‘reframing’ expectations and maintaining a positive outlook
- joint problem-solving
- being highly informed

Social support of friends:
- Seeking encouragement and support of friends
- sharing concerns with friends
- seeking information/advice from friends, particularly those who have experienced similar problems

Family dissolution and addiction:
- use of alcohol
- use of drugs
- use of gambling, leading to family psychosocial issues of loss, abandonment and breakdown

Communication
Maintaining links in
Family violence:
strategies:
- honesty and openness
- use of humour and laughter

the community:
- self-help groups
- spiritual supports, including religious affiliations
- more recently, social media networks

- partner abuse
- child abuse or neglect
- sibling abuse or neglect
- parent abuse

Source: Adapted from Friedman et al. (2003).

Clearly, families employ both positive and negative coping strategies when faced with stress. The serious or chronic illness of a child may cause families to react with guilt, fear, shock, uncertainty or grief (Jokinen, 2004), but then adaptive mechanisms will be employed to cope with the new ‘normal’. It is important to identify a family’s strengths and their available resources to guide them towards positive coping adaptation (Holtslander, Solar & Smith, 2013).

### Case study 3.1

**Audrey**

You are working in a small hospital in a rural area. Audrey is an 8-year-old girl who has been brought to the hospital by ambulance following a severe asthma attack at her home during the night. This is her fourth admission for asthma in the last six months, and she has missed her last two scheduled outpatients appointments.
Audrey is not accompanied by her mother in the ambulance. Her mother, Conchetta, arrives about an hour and a half later with her three younger children. Conchetta discloses that she could not come in the ambulance as her husband, Trevor, is a fly-in, fly-out mine worker who is currently away on a week-long shift.

Conchetta, 28, arrived in Australia six years ago from the Philippines with her daughter, Audrey, and is now married to Trevor, 53. They have since had three more children, now aged 3 years, 2 years and 6 months. They live in a rural area about 30 minutes’ drive outside a small town, where they are renting a house on 2 hectares. Conchetta states, ‘This always happens when Trevor is away. It is very difficult to cope with all the children when he’s away, but he is very helpful when he is home. I don’t know how I am going to spend time with Audrey this time in the hospital.’ Conchetta has no other family in Australia, but reports a close relationship with her church, and says she has a friend 2 kilometres away, with whom she is quite friendly, and a sister-in-law who provides occasional help with the children.

Considerations and challenges in conducting family assessments

It is essential that nurses perform effective family assessments so they can plan and provide appropriate nursing care (Wright & Leahy, 2013). Family assessment is often complex, but it is fundamental if we are to provide family-centred care and meet the needs of the child and their family.

However, it is often difficult in practice to perform effective family assessment, and there can be many reasons for this. To perform a detailed effective assessment, time is required, and this is often difficult to achieve in a busy clinical day (Marron & Maginnis, 2009). It is also important that
interruptions are minimised. As with any assessment process, the environment must be appropriate, with adequate privacy and comfort for the participants. The presence of the child or other children is often enough of a distractor without the busy clinical environment also impinging on the process. There are self-assessment tools that can be used, such as the McMaster Family Assessment Device. A shortened version of this tool has been found to effective in a recent Western Australian study (Boterhoven et al., 2015). This study found that this self-assessment tool was accurate in validating the functioning of families. Using self-assessment tools could prove useful in busy clinical environments where nurses are time-poor.

**Case study 3.2**

**Kylie**

Kylie is a 21-year-old mother to 6-month-old Skye, who has been admitted to the babies’ ward with severe nappy rash. Kylie is a patient in a methadone program as she struggles to overcome her drug addictions. Her partner, Steve, is a recovering alcoholic and has sole custody of his 3-year-old son, Lucas. Skye has been seen by the Suspected Child Abuse and Neglect (SCAN) team on a previous admission at 1 month of age for failure to thrive. Kylie and Steve live in a caravan park an hour’s drive from the hospital. In the few days since Skye’s admission, you have heard other nurses making very critical and judgemental comments about Kylie and her parenting ability. You have noticed that Kylie hasn’t been visiting as much during the day and did not stay overnight last night. When you ask Kylie how she’s going, she bursts into tears and says, ‘All you nurses are such bitches – you make out
like I’m a bad mother and I don’t need this crap. I’m taking Skye home right now. I don’t care if it’s against orders!’

When doing family assessments, it is necessary to form a therapeutic relationship with the family to encourage disclosure (Holtslander, Solar & Smith, 2013). Many nurses report discomfort with approaching more difficult topics such as child abuse or domestic violence, which may make them feel uncomfortable or challenged (Marron & Maginnis, 2009). This can be difficult for the family member to discuss, and may not be possible when the child or other family members are present. There can also be an emotional impact for you as the nurse, based on your own family experiences (Lee, Leung & Mak, 2012). Therefore, you need to be aware of your own feelings and prejudices when you are working with families, and be careful not to be judgemental or have preconceived ideas about what families should be or how they should behave.

When caring for children and families where domestic violence, substance abuse or child protection issues are present, it may be helpful to consider that such parents are experiencing their own multi-faceted health problems, which are often the result of their own adverse life experiences. A study exploring parent perspectives on their experiences with child-protection services highlighted that many parents who are engaged with child-protection services have themselves been subjected to abuse or rejection as children, and are often marginalised as adults (Maiter, Palmer & Manji, 2006). These experiences can undermine their ability to form effective relationships with others (Maiter, Palmer & Manji, 2006). In addition, mothers who are struggling with substance abuse have often been subjected to previous trauma in their lives, or may have mental health problems such as anxiety or depression (Cleveland & Gill, 2013). When
parents are being investigated in relation to child protection, they often feel extremely vulnerable and have the greatest need for support (Maiter, Palmer & Manji, 2006). Such mothers feel that they are constantly being watched and their parenting judged, with the possibility of their children being removed seen as an ongoing threat (Reid, Greaves & Poole, 2008). If, at these times, they are met with a lack of care or judgemental attitudes by health-care professionals, this can worsen their vulnerability and sense of isolation. Sadly, health-care professionals working with these families have been found to be judgemental and uncaring, and have labelled parents unfairly (Maiter, Palmer & Manji, 2006).

The relationship between nurses and mothers can have a powerful effect on the mother–child relationship and engender greater confidence and assertiveness in the mothering role (Cleveland & Gill, 2013). Nurses who express caring attitudes towards both mother and baby, and who engage mothers in the care of their infant, are valued by mothers who are struggling with drug addiction. Conversely, non-verbal behaviours such as eye-rolling, obvious surveillance and judgemental conversations among staff are a heavy burden for mothers, who perceive that nurses fail to see the person behind the drug addiction and don’t notice their efforts to be a good mother (Cleveland & Gill, 2013).

Nurses can empower mothers by ensuring that they collaborate with mothers, rather than treating them as if they are inferior. Reducing real or perceived power differentials is essential for an effective helping relationship (Carter, 2002; Maiter, Palmer & Manji, 2006). Some nurses working with mothers experiencing drug addiction describe working in parallel rather than in partnership with these families. Rather than embodying a family-centred care approach, they consider the baby to be the focus of care (Fraser et al., 2007). Nurses can speak out against unprofessional care and encourage mothers to make formal complaints if
they receive such care. They can role-model their regard and respect for the dignity of mothers like Kylie in Case Study 3.2. Nurses should also be encouraged to place mothers like Kylie in touch with supports who can continue to help them with their recovery from drug addiction. Small gestures from the nurse, such as giving a mother praise for positive interactions and good parenting of their child, can also have a positive impact. Parents appreciate health-care professionals who are genuine, empathetic, helpful, willing to listen, non-judgemental and accepting (Maiter, Palmer & Manji, 2006).

**Aboriginal and Torres Strait Islander family considerations**

Existing family-assessment frameworks have been criticised in terms of their use in Aboriginal and Torres Strait Islander families because of the diversity of family structure, geographical location and patterns of mobility among these families, as well as the limitations of these models in considering Aboriginal and Torres Strait Islander people’s identity, spirituality and social and community lifestyle (Walker & Shepherd, 2008). Between 2000 and 2002, a measure of Aboriginal family functioning was developed based on McCubbin and McCubbin’s (1989) model of family protective factors and administered as part of the Western Australian Aboriginal Child Health Survey. This measure of Aboriginal family functioning was developed in collaboration with Aboriginal health professionals, and consisted of nine statements about family functioning to which family members can respond in a five-point rating scale (based on the McMaster Family Assessment Device), from ‘not at all’ to ‘very
much’. The nine statements about family functioning for Australian Aboriginal families include:

- The way we get together helps us to cope with the hard times.
- We like to remember people’s birthdays and celebrate other special events.
- We find it easy to talk with each other about the things that really matter.
- We are always there for each other and know that the family will survive no matter what.
- When it comes to managing money we are careful and make good decisions.
- Our family has a lot in common in the interests we share and the things we do.
- People in our family are accepted for who they are.
- We have good support from our in-laws, relatives and friends.
- We have family traditions and customs we would like to pass on to our children. (Western Australian Aboriginal Child Health Survey, 2005: 602)

Family functioning in Aboriginal and Torres Strait Islander communities is often characterised by collective or socially inclusive child-rearing approaches, which may be quite different from those of other families, where concerns for child safety have resulted in protective behaviours among parents (Lohoar, Butera & Kennedy, 2014). Within this collective approach, the family, extended family and community share responsibility for the safety of children, and children are often encouraged to explore and
play independently in order to learn responsibility and to develop their self-confidence, autonomy and coping skills (Lohoar, Butera & Kennedy, 2014). Traditionally, Aboriginal and Torres Strait Islander families feel secure in allowing their children greater freedom to play and explore because of the ‘one community, many eyes’ collectivist approach. One parent described this community approach to caring for and protecting children:

Most of our families are connected … they are all connected. Like Cairns is a small place – most of the families are connected. If your boy does something down the street, someone will see it and that word is already going around and somebody would have rung the parent and said, look, I think something has happened but we don’t want to touch it because we know it’s your place.

(Lohoar, Butera & Kennedy, 2014: 4)

Elders also play a significant role in family functioning. They guide families and children towards an understanding of spirituality, the Dreaming and kinship, while teaching them to have respect for their elders and to care for each other within the community (Lohoar, Butera & Kennedy, 2014). Elders may not necessarily be chronologically ‘old’, and may include grandparents, aunts and uncles of varying ages.

**Cultural safety**

When approaching any family, the concept of cultural safety should be considered. Cultural safety was first introduced in the 1980s to encourage nurses to reflect upon their own cultural identities and attitudes, and how these might influence the way they interact with others (De & Richardson,
Nurses should not make assumptions about families based on gender, culture, ethnic, political or religious background, since these groups may not be homogeneous (Manchester, 2013). However, these considerations can be incorporated into your family assessment. It is important to remember that culture is not necessarily linked to ethnicity, although this is a common belief (De & Richardson, 2008; Manchester, 2013). We are all members of many cultures, and this will change as we move through life stages and our needs alter (Friedman et al., 2003). For example, as a nursing student you are part of the university culture and way of life, and you will move into the workplace culture when you graduate. You will move through many different cultures in your personal and professional life.

Developing an understanding of the individual family’s cultural, ethnic and spiritual perspective will assist you to understand the family and their needs, which contributes to care planning. Asking open-ended questions can lead to deeper exploration of these topics. This will help you understand the family’s needs and members’ basis for decision-making in order to provide culturally safe, sensitive and individualised care (McEvoy, 2003).

These are some of the reasons why, in practice, a detailed family assessment is often not performed or is ineffective. As a nurse, you need to identify those children and families requiring detailed family assessment. This may involve referral to other health professionals – particularly social workers, who are experts in interviewing and family assessment.

Summary
Within paediatric nursing, the patient is considered to be both the child and all members of their family. Nurses need to assess, plan, implement and evaluate care in conjunction with the child and family.

The Family Partnership Model and family-centred care are two models that recognise the centrality of families in paediatric nursing and encourage nurses to work in partnership with families to ensure optimal health outcomes for the child and their family.

Family assessment is integral to the effective care of children and families, and incorporates consideration of family composition, structure, family development/life-cycle stage, roles and functioning, stressors and coping strategies.

When conducting family assessments, nurses need to be mindful of their verbal and non-verbal communication skills, the environment, and their own influences and perceptions, which may consciously or unconsciously impact on communication with and assumptions about families.

**Learning activities**

3.1 Re-read [Case Study 3.1](#). Draw a genogram of this family’s structure. Try drawing an ecomap of Conchetta’s support system.

3.2 Based on your reading so far, what life-cycle stage is this family in?

3.3 Some aspects of this case study may challenge your belief system. Consider these and explain why this may be so.
3.4 What are the stressors for both Audrey and Conchetta? Write these down and then consider how these could be useful when planning care for Audrey in the context of her family.

3.5 What are some of the risks you can identify for this family? What are some positive coping strategies with which you could assist Conchetta?

Further reading


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**Genogram** – A visual representation of a family’s structure and relationships in respect to the patient of focus. Some may also include ages and health problems.
Ecomap – A visual representation of the identified supports of the family unit

Emotion-focused coping – A style of coping where individuals use strategies such as distancing, seeking emotional support or avoidance in order to manage negative emotions

Problem-focused coping – A style of coping where individuals take a planned approach to addressing problems, using strategies such as information-seeking and decision-making

Meaning-focused coping – A style of coping often found among individuals encountering life-changing events, such as critical illness or the loss of a family member. Individuals draw upon their inner beliefs and values, revise goals, focus on the strengths gained from the life experience and reorganise their priorities.

Cultural safety – Awareness of one’s own cultural identity and attitudes, and how these might influence patient care; implementing care that is acceptable to and promotes a sense of safety among patients and their families, regardless of background or cultural identity
4

Psychosocial development and response to illness

Jennifer Fraser and Robyn Rosina

Learning objectives

In this chapter you will:

- Be introduced to the ways in which children, young people and their families respond to disruptions in health
- Explore the relationship between responsive nursing practice and psychosocial development of children and young people
- Examine cultural factors that influence the ways in which children, young people and their families respond to disruptions in health
- Consider child behaviour and child development, and the impact of nursing practice on responses to experiences of illness
- Identify health-promotion and health-education strategies that aim to improve the health and wellbeing of Australian children
Introduction

This chapter pays special attention to the responses of children, young people and their families to disruptions to a child’s health. When a child experiences an acute or chronic illness, we can expect a number of emotional and behavioural responses. The paediatric nurse’s knowledge of child behaviour and child development can be of great benefit in assisting parents and caregivers to promote resilience in the child or young person.

This chapter presents a series of case studies and case study resolutions to provide guidelines and recommendations for managing emotional and behavioural disorders related to children’s experiences of illness. The case studies are presented within a framework of psychosocial development to best illustrate the relationship between child development and response to illness. The relationship is bidirectional – that is, responses are shaped according to the developmental stage of the child or young person, and development is impacted by the experiences of both acute and chronic illness. Consideration is given to cultural and social factors that influence the child’s response to the experience of illness. This includes Aboriginal and Torres Strait Islander health considerations and the potential implications for care provided to children, young people and their families.
**children and young people experiencing disruptions to health**

Opportunities for developmental experiences that promote healthy psychosocial development may be limited or compromised by childhood illness. The presence of chronic illness may disrupt the pace and timing of developmental milestone achievements. Indeed, regression of previously mastered milestones may be observed. Long absences from school and limited opportunities for taking responsibility and the experience of achievement can compromise psychosocial developmental mastery. For some younger children, the inability to play and the absence of a playgroup can reduce opportunities for developmental progress. The feelings of difference from peers and the experience of an inconsistent peer group make it even more difficult for some young people to achieve developmental milestones.

The sequencing and progression of psychosocial development are shaped by day-to-day life experiences and interactions, both within families and with other people in the community (Erikson, 1968). Children and young people with **chronic illness** often have extended hospital admissions that result in the child being isolated from family members and peer groups. Periods of life-threatening crises, persistent anxiety and distress, endurance of pain and long **hospitalisations** can limit developmental experiences for psychosocial task experimentation and mastery. Longer-term outcomes may result, including behavioural and mental health issues, learning problems and vocational challenges.

Further challenges emerge when the physical effects of the disease and treatments, such as short stature, weight gain or loss, disabilities, jaundiced skin colour and (for some) hair loss, increase the sense of difference from well peers (Gurney et al., 2003). There are numerous
environmental mediators that can act as, or become, protective factors when an individual is faced with developmental compromise. These environmental factors can also be risk factors (Turkel & Pao, 2007). Other factors, such as the severity and visibility of the illness, current health state, duration of the illness and time since diagnosis, can also impact on the developmental environment to predispose or protect the young person from the adverse effects of illness on psychosocial development (Falvo, 2013). However, the relationship between these factors and moderation of the environment is complex.

Following the stages proposed by Erikson’s (1968) theory of psychosocial development from infancy through to young adulthood, the chapter will now examine the impact of pain, illness and disability, and the responsiveness of nursing practice. The six psychosocial developmental stages are:

1 trust versus mistrust: infancy (first year of life)
2 autonomy versus shame and doubt: infancy (second year of life)
3 initiative versus guilt: early childhood – the preschool years (3–5 years)
4 industry versus inferiority: middle and late childhood (infants and primary school – 6 years to puberty)
5 identity versus identity confusion: adolescence (10–20 years)
6 intimacy versus isolation: early adulthood (twenties and thirties).

Trust versus mistrust: Infancy (first year of life) and the sick infant
Erikson’s first psychosocial developmental stage, from birth to 1 year, begins with the conflict of basic trust versus mistrust. According to the theory, this conflict is resolved if the infant experiences a sense of trust about having their needs met without high levels of anxiety or distress. For example, the situation of distress may arise for infants while waiting for care in busy hospital wards or with inconsistent caregiving or the absence of parental care. Delays in the gratification of the infant’s needs and persistent anxiety can induce a poor or negative resolution of the conflict of trust versus mistrust. A negative resolution of this stage can result in feelings of mistrust and anxiety about the responsiveness of the environment to meet the infant’s needs in the future (Erikson, 1968).

The resolution of this first developmental stage is also important to the process of attachment to a caregiver in infancy. Bowlby (1969), a major attachment theorist, proposed that it is in fact the infant who elicits care by a series of built-in behaviours such as crying, sucking, clinging, gazing and smiling. These behaviours trigger a caregiving response – that is, rather than the parent initiating caregiving, it is the infant who initiates this responsivity to cues. The caregiver, however, needs to be sensitive to these cues in order to respond appropriately to the infant’s needs. In the case of a sick infant, distance from the primary caregiver can result in separation anxiety and an anxious attachment style (Bowlby, 1969). This situation may compromise the development of trust inherent in Erikson’s stage of trust versus mistrust. The post-natal stage of development is a ‘sensitive period’, when bonding can occur and attachment to a consistent caregiver – ideally a parent – can begin (Newman & Newman, 2011). Clearly, illness and hospitalisation during early infancy can put the quality of attachment and the developmental task to accommodate a sense of trust for sick infants at risk.
According to the theory of human attachment, child development throughout infancy and toddlerhood is grounded in the security of the parent–infant relationship (Ainsworth et al., 1978; Bowlby, 1951, 1969, 1988). Developmental problems among hospitalised infants and toddlers appear to relate to limited opportunities for nurturance by caregivers, as well as to how the child adapts to the environment over time. These two themes of parent–infant attachment and adaptation to the environment dominate the literature on the effects of frequent hospitalisation on children’s development.

**Case study 4.1**

**Luka**

Luka was born with a congenital cleft lip and palate. He is admitted to the paediatric surgical unit for the first of a series of operations to repair the anomaly at 10 weeks of age. On admission, the nurse notices that his mother always faces him away from her own face, towards you. She does not kiss him or speak to him warmly. She hardly speaks to the nurses about him or his care unless encouraged to do so. In fact, she is noticeably avoidant of her young son. When the child tries to engage with a little smile or with his eyes, the mother turns away and looks at her mobile phone. She does not respond to any of his desperate cues to gain her attention.

A paediatric nurse will recognise subtle cues and understand the developing capabilities of children at different stages. An infant with a mild temperament, engaging communication style (smiles often and maintains eye contact) and an attractive physical appearance will elicit more positive interactions with caregivers.
and staff compared with infants who do not engage well, who cry often or whose medical condition requires minimal handling. In Luka’s case, it would be important for the paediatric nurse to identify the possibility that his mother is not responding to his cues for attention. The reasons for this may be complex, and understanding her behaviour may require further assessment. In the meantime, an important goal would be to help her to identify that this is a problem for Luka, as it threatens his ability to develop good communication skills and will affect his attachment style. That is, a consistent and responsive mother can help Luka learn to trust and communicate, and consequently to develop to his full potential.

It is just as important to optimise opportunities to promote the growth and psychosocial development of hospitalised infants through careful observation and timing of nursing interventions. With access to the hospitalised child around the clock, actions can ameliorate the psychological impact of hospitalisation and potentially reduce the stress of the child’s suffering.

Even children with verbal skills and the ability to communicate easily may not be capable of explaining their symptoms, and the impact of hospitalisation or the experience of illness. This ability relies on a range of developmental factors. Recognition of a child’s stress response is the trigger to identify measures that can modify stressors and help decrease the impact of experiences such as pain and emotional distress. Accurate assessment data are needed. These are usually gathered from parents or caregivers, and include details of familiar routines that are usual or normal for the child, as well as developmental milestones. Communication and cognition skills are not fully
developed in the young child, leaving the nurse to rely on parents or other significant caregivers for information.

**Attachment theory**

John Bowlby, influenced by Freud’s work, was the seminal attachment theorist. Bowlby formulated the concept that children are born biologically pre-programmed to form attachment to people as a secure base to enable survival (Bowlby, 1969, 1988). After testing Bowlby’s assumptions, Ainsworth established the concept of the attachment figure or secure base from which the infant can explore the world (Ainsworth et al., 1978). In addition, Ainsworth added to this theory the concept of maternal sensitivity to infant signals and its role in the development of the infant–mother attachment (Bretherton, 1992). The work of both Bowlby and Ainsworth continue to provide strong evidence for the key tenets of attachment theory.

**Reflection points 4.1**

- Family-centred care is based on the tenets of attachment theory, in recognition of the importance of maintaining a secure attachment relationship in infancy and childhood.
- Sick infants and toddlers need ongoing opportunities for nurturance by caregivers to prevent developmental problems associated with hospitalisation.

**Case study 4.2**
Evie

Evie, aged 11 months, was admitted to hospital at 4.00 am with respiratory distress and diagnosed with bronchiolitis. Her oxygen saturations go down when she gets upset. Her mother has had to go home to care for her other three young children. Evie’s parents both work shifts. Her father will be able to arrange to take some time off from his job to assist with child care, but for now Evie’s mother needs to be at home to take care of Evie’s siblings. Evie eats a normal family diet supplemented with bottles of formula four times a day. She has been screaming and crying out for her mother ever since she left 20 minutes ago.

Evie clearly has a strong attachment to her mother. In her mother’s absence as a secure base and caregiver, Evie’s distress is evidenced by her reduced oxygen saturation. Factors that can exacerbate traumatic reactions to the hospital experience for young children include emotional distress, painful procedures and traumatic stress, which can have long-term consequences. Inconsistent caregivers and changes in routine can further contribute to distress in hospitalised young children. Exploring options for supportive child care for Evie’s siblings, ensuring a regular routine of care for Evie, good pain management, rostering the same nurses to provide consistent care and ensuring quick and consistent responses to distress could ameliorate the potential adverse effects of hospitalisation. These are just some of the considerations a paediatric nurse might consider to mitigate the emotional and physiological impact of trauma associated with separation from parents and family while in hospital.

In order for the nurse to decide how best to care for Evie until her mother can return in the evening, the nurse needs to understand
that a child’s reaction to hospitalisation depends not only on the developmental maturity of the child, but also on:

- their previous experience of hospitals and illness
- separation and their resilience to being separated from the primary caregiver
- their innate and acquired coping skills
- the seriousness of the illness or disability
- the quality of support networks the family can access.

As mentioned previously, separation from the primary caregiver creates the greatest stress for young children in the first year of life and in the preschool age group. Separation anxiety manifests as initial protesting and crying when the caregiver leaves the infant. This is especially characteristic between 9 and 11 months of age, but can be experienced throughout childhood. This is followed by a period of despair and withdrawal, when the child will appear depressed. They may be less communicative and regress developmentally. If separated further – that is, if the parent fails to reappear – the child will become detached from the external environment and develop superficial relationships with others as they adjust to separation (Ainsworth et al., 1978). Good planning and attention to the developmental needs of the child are needed to reduce Evie’s risk of separation anxiety.

**Nursing assessment and interventions**

Strategies to reduce the impact of separation anxiety are based on a detailed assessment of the seriousness of the child’s condition, the family’s
previous experience of childhood illness and hospitalisation, and the medical procedures that will be necessary for an optimal recovery. Where the parent is unavailable during the child’s hospitalisation, there are a number of key elements of care that the nurse should know and understand. Importantly, the child’s routines – especially their dietary requirements – must be documented carefully. Planning care around usual activities and familiar routines may be challenging, but the benefits of having a relaxed child will outweigh the inconvenience. A favourite toy and some familiar books might assist in soothing Evie while her mother is absent. If possible, assist the mother to problem-solve so that she can make staying with Evie in hospital a priority. For example, prompt her to think of responsible friends or relatives whom she could trust to care for her other children. Seek advice about any other relatives familiar to Evie who might be able to stay in hospital at times when she cannot. It has been recognised for some time that affectional ties with parent substitutes such as grandparents and older siblings, which encourage trust, autonomy and initiative, aid in the healthy and optimal development of young children (Werner & Smith, 1992: 192). Parents, as well as their children, are stressed at times of illness and hospitalisation, and assisting with problem-solving can be very helpful and comforting.

**Autonomy versus shame and doubt:**
**Infancy (second year of life) and the sick toddler**

Erikson’s second stage of psychosocial development, from 1 to 3 years, involves resolving the conflict of autonomy versus shame and doubt (Erikson, 1968). The child’s discovery of a will of their own marks this
stage. The child begins to walk and climb, and develop the mental powers to make decisions. Autonomy begins to form during this stage, when parents or caregivers offer guided choices and do not overly restrict, force or shame the child (Erikson, 1968). Children who are restrained too much or punished too harshly may be at risk of developing a sense of shame and self-doubt (Erikson, 1968). For young children with chronic illness, the achievement of milestones such as walking and climbing may be impossible or delayed by the impact of the disease process. Incapacity and physical limitations may also compromise the attainment of a sense of competence for children with chronic illness.

The diagnosis and treatment of chronic conditions often involves multiple painful procedures that can risk traumatic stress for the child, parents and siblings (National Child Traumatic Stress Network, 2016) and/or anxiety disorders (Pao & Bosk, 2011). The hospital experience can become an extremely stressful period for both the child and the family. The anxiety that a child may experience during invasive and traumatic procedures can have long-term psychological consequences (Pao & Bosk, 2011; Turkel & Pao, 2007).

A common reaction to stress in children is regression of developmental gains. The young child who was toilet trained may need to wear nappies again until they become more resilient in a stressful situation, and the toddler who was beginning to dress independently may need some assistance while in hospital. The extra attention paid to the child will assist with the adjustment to hospitalisation. Parents can become quite distressed to see their children regress in this way, and need to be reassured that this is generally a temporary and expected response to the stress of illness and hospitalisation. Patience and understanding are needed, and the nurse may use strategies such as modelling the behaviours and providing anticipatory
guidance, thus preparing the parents for the extra care and attention the child will need to overcome stress (see Box 4.1).

**Box 4.1** Nursing assessment and interventions

- If possible, prepare the child for hospitalisation.
- Prevent or minimise separation from caregivers.
- Prevent or minimise loss of control.
- Provide excellent pain management.
- Provide age-appropriate play equipment.
- Provide opportunities for the child to play.
- Allow regression and assist parents to accept immature behaviours.

**Initiative versus guilt: Early childhood - the preschool years (3–5 years)**

According to Erikson’s theory of psychosocial development, the third stage, from approximately 3 to 5 years, is marked by courage and independence (Erikson, 1968). The child gains initiative and is capable of planning and problem-solving. With this stage also comes a new emotion: guilt. Children at this stage of development may experience a feeling of guilt when their initiatives are unsuccessful.

Case Study 4.3 involves David, an 11-year-old boy with Down syndrome. Erikson’s conflict of industry versus inferiority is a particularly
important and critical stage and milestone for many children with disabilities. David’s story highlights the importance of recognising developmental mastery among children with disabilities, and the key role played by nursing practice in influencing the hospital experiences for this group. The case example of David highlights not only the importance of identifying anxiety but also how difficult it is to recognise behavioural developmental cues and to ensure responsive nursing care.

**Case study 4.3**

**David**

David has been admitted to hospital for further medical management of congenital heart defects that are now impairing his cardiac function. Prior to admission to hospital, David was able to assist with dressing and, after prompting by his mother, Kath, could almost use the toilet by himself. Early in the admission, the insertion of a cannula was required to administer antibiotics. David thrashed about violently and needed to be restrained for the procedure. After the procedure, David remained aggressive and incontinent, spitting and refusing to swallow medication. He eventually pulled out the cannula. Kath became visibly distressed and later disclosed feelings of helplessness, powerlessness and an inability to control or even influence her son’s experience in the hospital. When at home, even when David was sick, she was able to control or at least soothe and make things easier for her son. Kath also felt her son was aware of her distress and her inability to protect him, which always made his behaviour worse.

The anxiety levels of mothers are reported to be a powerful predictor
of anxiety among children in this age group (Smith & Kaye, 2012). Insight into maternal anxiety can also provide a window to assist the nurse to understand, predict, identify and perhaps intervene with distressed children (Luyckx et al., 2008). Understanding and ameliorating maternal anxiety may potentially be another environmental mediator that could help reduce the anxiety of hospitalised children and facilitate resolution of the conflict of industry versus inferiority. At the very least, it may prevent developmental regression and the loss of previously acquired or current achievements. In the case of David, it may have been a loss of previously attained skills and current developmental mastery, such as toileting, feeding himself, feeling safe and being able to control his behaviour.

Parents’ and carers’ perspectives and knowledge of the child’s mood and behaviour, and particularly the information they can provide about premorbid function, are extremely valuable in understanding the child’s psychosocial functioning and current state. In particular, with children such as David it could be useful to explore previous developmental achievements – specifically emotion regulation, feeding, bathing or the level of support required for these activities. Young children often find it more difficult to articulate their distress in a meaningful way; this is particularly apparent in children with developmental delays. A mild sedation for David and appropriate preparation for the traumatic procedures, both for David and his mother, may have reduced the need for restraint and the level of anxiety that ensued. Routine monitoring of mood, emotions, behaviour and functioning before and after traumatic procedures can identify rising anxiety for both parents and their children. Identifying anxiety can create opportunities to ameliorate distress and avoid losses in developmental mastery during hospitalisation and at home after discharge.

Nursing interventions that target maternal anxiety are important when it comes to moderating the anxiety of children undergoing traumatic
procedures. A randomised control trial was conducted to explore the effect of interventions targeting maternal anxiety and depression among 163 mothers of hospitalised children in two paediatric hospitals. The level of anxiety and depression among the group was measured at intervals of one, three, six and 12 months after hospitalisation (Melnyk et al., 2004). The study showed that the use of specific interventions to reduce maternal anxiety strongly reduced child anxiety and resulted in fewer negative behaviours after discharge. The researchers concluded that with routine provision of interventions that reduce maternal anxiety, negative outcomes such as developmental regression following discharge could be reduced substantially (Melnyk et al., 2004). Nursing interventions that empower the child and/or normalise the hospital experience as much as possible – particularly for children with developmental delays – may promote developmental opportunities. Interventions that consider the challenges to optimal child development can also promote the retention of previous levels of developmental mastery. Developmental regression can weaken opportunities to resolve and master later developmental conflicts and milestones, such as moving from childhood to adolescence, so this stage is clearly critical in optimising children’s self-care and independence as adults.

**Reflection points 4.2**

- The nurse cares for the child, parents and family in paediatric nursing settings to optimise the child’s health.
- Acknowledging maternal anxiety can reduce the anxiety of hospitalised children.
Parents and caregivers are the cornerstone of their children’s health decisions and behaviours. Working with parents to achieve optimal health, growth and development requires an understanding of the impact on parent functioning of caring for a child with a chronic condition or disability. Not only are the parents responsible for the child’s treatment regimen, emergency care responses and daily care routines; they are also responsible for the day-to-day management of the child’s condition. An important consideration for nurses caring for David is the fact that children with chronic illness and disability are at higher risk of suffering child physical abuse (Svensson, Bornehag & Janson, 2010). As discussed in Chapter 2, the paediatric nurse has a responsibility to detect and respond to the recognition of child abuse and neglect. Children are vulnerable due to their dependence on adults for care, having their developmental needs met and living in harmony.

There is ongoing concern for the increased vulnerability of children with chronic illness and those with longer-term disabilities. Svensson, Bornehag and Janson’s (2011) Swedish survey of 2510 children aged from 10 to 15 years with a chronic illness and/or disability found that the risk for physical abuse was high compared with unaffected peers. Likewise, a retrospective study of all children reported as abused or neglected between 1977 and 1984 revealed that chronic illness placed children at higher risk of neglect during the same period. Taken together, the evidence for children with chronic illness and disability being at risk of emotional,
behavioural and social delay, and their increased likelihood of suffering child abuse and neglect, demonstrates their overwhelming risk. It also points to the importance of paying attention to the family environment and family functioning.

A review of the related literature (Morawska, Calam & Fraser, 2014) highlights that the characteristics of the family environment and the severity and chronicity of the illness, rather than the specific childhood illness, are the best predictors of adjustment to chronic illness in childhood (Svavarsdottir & Orlygsdottir, 2006). These are important findings, guiding our understanding of the poor emotional or behavioural adjustment in comparison with children without a chronic illness across a variety of settings (Blackman et al., 2011; Hysing et al., 2007, 2009). That is, whether the child is cared for in the respiratory, endocrine, oncology or medical ward, we can expect to have to manage children and families struggling with adjustment disorders. Internalising conditions, such as depression and anxiety, and externalising disorders that feature behaviour problems and aggression (Pinquart & Shen, 2011), social difficulties (Meijer et al., 2000) and using the illness to avoid school and other responsibilities (Eksi et al., 1995) will need to be acknowledged and managed. Of particular importance during hospitalisation is the risk of poor social development. Children who present with poor social skills will find hospitalisation extremely stressful and should receive extra attention (Lambert et al., 2013; Meijer et al., 2000). Externalising behaviours may also be experienced. Parents commonly adopt a permissive parenting style for the child with a chronic condition, fearing that discipline may add to the stress of their life. Unfortunately, this can result in poor regulation of the child’s own emotional reactions. Reactions to injury and illness include crying, resistance and oppositional behaviour, and aggressive outbursts. As the child develops, the concerns become more complex. The young child
may fear disability and lack of privacy, and use words more effectively to describe fear and pain. School-aged children are especially vulnerable to stress as they struggle for independence and seek peer acceptance.

**Industry versus inferiority: Middle and late childhood (infants and primary school – 6 years to puberty)**

Social and cultural factors also play a key role in the way children in the fourth stage of psychosocial development respond. According to Erikson (1968), this is an important stage in the development of self-confidence. Children in this stage are likely to be able to form moral values, and work hard to get things right. They are capable of recognising cultural and individual differences, and can express their individuality and independence.

Fine motor coordination increases during this stage, and children in this age group are capable of completing complex motor tasks. This improves their ability to play games that require hand–eye coordination, such as soccer and handball, and extends to having the physical skills to become involved in complex health procedures, such as applying creams and independently managing bandaging.

Perceptual thinking moves towards conceptual thinking – that is, the child moves from a way of thinking based on what they see (perceptual) to judging a situation based on their own reasoning (conceptual). Towards adolescence, concrete thinking matures. Abstract thought and a greater understanding of their health condition mean that children of this age have more agency in determining their own health behaviours. They are able to contribute more to discussion and decision-making. Children of this age
often have a strong sense of industry, and enjoy accomplishment that can be harnessed into positive health behaviours and greater responsibility. Treatment and treatment outcomes may deteriorate at the end of this stage as young children attempt to participate in, or are strongly encouraged to take some responsibility for, their treatment and general health care. Behaviour problems are common as children strive to test their skills in their own way.

Interestingly, in relation to parenting style, authoritative parenting styles are associated with better management of childhood illness, and with superior child adjustment (Botello-Harbaum et al., 2008; Park & Walton-Moss, 2012). Higher rates of emotional and behavioural problems among children with chronic illness may be explained by their parents’ expectations of behaviour and a reluctance to discipline a sick child (Ievers et al., 1994). Understandably, parents may set different expectations for their child’s behaviour, especially during hospitalisation. A high level of parenting stress and low parenting self-efficacy are known to reduce parents’ ability to manage their children’s behaviour, and to manage treatment regimens crucial to the management of childhood illness (Helgeson et al., 2011; Streisand et al., 2005)

**Australian Aboriginal and Torres Strait Islander families**

The determinants of health for Aboriginal and Torres Strait Islander families in Australia are tied to cultural, historical, social and economic conditions. The social determinants of health include:

- employment
- a sense of feeling safe in their community without discrimination
- participating in or already having a good education
• having enough money for their needs
• feeling connected to friends and family
• a connection to their land and the historical past that took people from their traditional lands away from their families (Carson et al., 2007)

The national strategic plan for health and health services in Australia, the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 (Australian Government, 2013) has set out an agenda for responsive health care. Aboriginal and Torres Strait Islander children and families are over-represented in health and welfare services, as detailed in Chapter 1. Nurses working in paediatric settings throughout Australia are encouraged to familiarise themselves with this plan. Aboriginal people continue to have lower life expectancies and poorer health than other Australians. The social determinants of Aboriginal health include historical factors, education, employment, housing, environment, social and cultural capital, and discrimination (Australian Government, 2013). The consequences of Aboriginal people being taken away from their traditional lands have been devastating, not only in terms of social and economic conditions but also for subsequent health status. This situation has led to fewer life opportunities for this group, and has directly contributed to health disparities for Aboriginal and Torres Strait Islander children in many communities across Australia:

Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-
being of their community. It is a whole-of-life view and includes the cyclical concept.

(Department of Health, 1989)

As a result of inequities in the social determinants of health experienced by Aboriginal and Torres Strait Islander people in Australia, they not only experience more health problems but also face greater barriers to accessing services that could assist them to improve the health of their children and families. The following case study of Lana illustrates the struggles Aboriginal families face living in rural and remote New South Wales.

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**Lana**

Nine-year-old Lana, an Aboriginal child living in an outer regional area of New South Wales, has chronic eczema. She has been sent in from her community to a tertiary paediatric hospital with infected eczema. Lana lives with her parents and five siblings on the outskirts of a small rural town. A number of issues have been identified that prevent the success of Lana’s eczema treatment and result in recurrent skin infections.

**Psychosocial and family issues**

- Lana’s mother has difficulty accessing and paying for sufficient creams and bandages to complete the eczema treatment regimen.
- Lana’s father is out of work and without transport to seek work.
A couple of Lana’s siblings have recurrent ear infections. The community has difficulty obtaining regular garbage collection, and as a consequence the garbage is stacked up at the entrance. The children are attracted to the garbage to explore and play.

A number of dogs wander through the community and are also attracted by the garbage. The children love patting the dogs.

Lana’s parents – and indeed the whole community – have numerous pressures placed on them. The ability to provide complex care is compromised by poverty and poor housing. Paediatric nursing care involves the child or young person and their family, because it is the family environment that shapes child health outcomes and emotional and behavioural adjustment. The child’s response to illness experience is shaped by the influence of parenting capacity as well as family stress (Morawska, Calam & Fraser, 2014).

Interprofessional connections
Lana requires a family and community response that engages with a range of agencies to improve the resources available to her family if they are to care effectively for Lana’s chronically infected eczema. Lana’s treating doctor provided a plan for the treatment of her eczema; however, this time an inter-agency response was developed to assist her family to execute the plan. Below are the people and agencies that came together for the case conference (or relayed input by phone) at the Aboriginal Health Centre in the nearest town. They included:
Lana and Lana’s parents

> a paediatric outreach clinical nurse consultant via teleconference from the paediatric hospital and then handed over the Aboriginal health worker

> an Aboriginal health worker

> an Aboriginal welfare officer

> the local hospital pharmacist

> the local pharmacist

> an NGO employment agency

> Aboriginal elders (Lana’s aunties)

> a community worker with the local council

> a general practitioner (GP) (for Lana and her siblings).

Following discussion, a community plan was put in place for Lana and her family. The plan assisted her father to regain employment; the council to manage the roaming dogs; Lana’s aunties to assist her mother with the care of the other children; transport for Lana and her siblings to reconnect with their GP; and the community workers to negotiate with the local council to ensure regular garbage collections.

Lana’s situation – or, rather, her family’s determinants for health – improved immensely. Resources were made available for the family to determine their own health. The role of the paediatric CNC was reduced to periodic reviews and assistance with supply issues obtaining the necessary creams and bandages. Lana was seen at the paediatric hospital two years later for a hearing
problem. Her eczema had almost resolved, and she had not had any further infections.

Note: Throughout the case study, we have used terms for Aboriginal and Torres Strait Islander people as advised and with respect. We hope this does not offend Aboriginal and Torres Strait Islander people.

Sources: Northern Sydney Local Health District Aboriginal Health Services (2013: 6) and personal communication through Wollatuka Institute of Aboriginal Studies at University of Newcastle, 15 August 2016.

Cultural considerations

Cultural influences and family factors play a large part in the way children experience health and illness. Cultures are not homogeneous, but those of the same culture often experience similar health and social issues. The family unit itself is culture at a foundational level, and health beliefs and parents’ health practices for their children vary within and between cultures. Recognising and accepting heterogeneity within and between families enables the paediatric nurse to provide care that the family is more likely to accept. There are direct and indirect aspects of culture that impact on the individual’s actions and beliefs. These include race, family values, customs, health beliefs and practices, child-rearing practices and susceptibility to certain health problems.

Around the world, families are moving from country to country to seek better living conditions and opportunities to improve their health and social status. A number of these families and individuals settle in Australia, bringing with them health and social issues from their country of origin and the countries en route to seeking asylum in Australia, as well as
the additional concerns of settling in new country and culture. As nurses, we can expect to be confronted with complex issues requiring responsive clinical assessment and practice.

**Case study 4.5**

**Aarfah**

Aarfah is a 9-year-old girl who came to Australia by boat from Iraq via Indonesia and lives in a detention centre. She was brought to the hospital with her mother after three days of abdominal pain and vomiting. The detention centre nurse had decided the dehydration could not be managed at the centre and required hospitalisation. Aarfah’s family had experienced significant trauma as a result of war in their home country and fear of discovery while waiting in Indonesia for a boat to Australia. Aarfah’s living conditions became quite poor and she and the other children suffered from many infections. Aarfah’s mother explains through an interpreter that her daughter has suffered night terrors since leaving the family home in Iraq and her much-loved school friends.

Aarfah’s struggles with health had preceded her current abdominal pain and vomiting. Her viral illness was soon diagnosed and resolved quickly with the appropriate treatment. Her abdominal pain became more general ‘pains’, which continued despite her recovery from the virus. It was clear that Aarfah was not recovering as expected for a 9-year-old. She was uninterested in playing with her peers, teary and at times was seen hitting her mother. Aarfah’s ‘pains’ and night terrors persisted.

A referral was made to a child psychiatrist in consultation with Aarfah’s mother, using an interpreter. Following extensive
family and child assessments, a diagnosis of Post-Traumatic Stress Disorder (PTSD) was made and appropriate treatment commenced. Aarfah was discharged back to the detention centre with a care plan that included ongoing counselling and child and family psychological interventions. Some three months later, Aarfah attended a clinic appointment for immunisation and was seen by the Consultation Liaison Child Psychiatry CNC and Registrar (CL Team). Aarfah’s physical health and mental state had improved and she was interacting normally with her mother, clinic staff and in play. Her mother reported that her daughter no longer experienced night terrors; she was playing with her siblings and participating in school activities at the centre.

The determination process for asylum seekers to achieve refugee status is lengthy in many countries like Australia. Asylum seekers and refugees have a higher risk of physical disease and mental illness as a result of poor living conditions, poor nutrition and an inability to access appropriate health care and economic resources to effectively care for themselves and their families (Hadgkiss et al., 2012). They often suffer from enduring stress as a result of their experiences in their war-torn homelands, on their journeys to Australia and while in detention. Children are especially vulnerable to PTSD and other mental disturbances and behaviour problems (Hadgkiss et al., 2012).

Reflection points 4.3

- Paediatric nurses require a comprehensive understanding of the lives of asylum seekers and refugees alongside information about their health and social needs.
Identity versus identity confusion: Adolescence (10–20 years)

As children move from childhood into the adolescent years, different developmental issues arise. Assuming the management of their own health and treatment regimens becomes increasingly important. The impact of their illness on their physical and psychosocial development becomes more tangible and personally real to the young person. For some young people and their families, this can be quite overwhelming.

Erikson (1968) marks the period of adolescence, from ages 10 to 20 years, as the fifth stage of human psychosocial development. This stage presents the conflict of identity versus identity confusion, and the transition from childhood to adulthood. The achievement of the earlier developmental tasks, regardless of the quality of mastery, becomes integrated into a lasting sense of identity and an emerging recognition of one’s place in society. A more negative outcome is recognised by identity confusion, sexual identity and future occupational potential.

The achievement of a sense of identity is a particularly critical stage for optimal independent functioning and mental health for young people with chronic illness. Young people with chronic illness may spend long
periods in hospital or be confined largely to their homes. This situation limits the experience of a social context of peers and the community to work on the developmental conflict of identity versus identify confusion. Other vital experimentation with roles, normal levels of risk-taking behaviours and the development of cognitive abilities have the potential to be limited. The cumulative effect of experiencing fewer developmental experiences and poorer psychosocial development becomes apparent during adolescence. Given that some children and young people spend so much time in hospital during infancy, childhood and adolescence, nursing practice has the capacity to create opportunities for psychosocial growth and development through day-to-day hospital experiences.

Erikson believes that it is not the rapid growth and sexual impulses *per se* that disturb adolescents, but rather an acute fear of being different or of not conforming to a peer group. Clearly, for the chronically ill young person, this situation can cause increased anxiety. Young people also worry about the future and how they will be able to lead an independent life (Erikson, 1968). The visibility of a disease, in terms of physical difference from peers and forced dependence on others for care, presents major developmental challenges to the conflict of achieving a sense of identity. More often, the developmental trajectory does not conform to the timing and tempo of peers’ development. Clearly, an open-mind and astute developmental mastery skills are essential to adolescent health nursing practice.

In Case Study 4.6, Ellen, her family and the nurses, within an interprofessional team, work through a number of challenges. For Ellen, these include psychosocial developmental trajectory disruptions; for her family, anxiety and grieving issues; and for the nurses and the interprofessional team, professional challenges to eventually provide
developmentally responsive health care that optimises both medical and psychosocial outcomes.

### Case study 4.6

**Ellen – a young person**

Ellen is a 16-year-old young woman with cystic fibrosis (CF). The treatment of CF for Ellen includes physiotherapy three times a day, nine enzyme replacement tablets with each meal as well as nebulised medicines twice daily and an average of four hospital admissions each year. Ellen prefers to keep her illness a secret from her peers. She had an earlier experience with a young man who, when he learned Ellen had a terminal inherited disease, did not want to continue seeing her. The young man believed Ellen might die during sexual intercourse or, worse, that she might become pregnant and the disease would affect the child. Ellen has dreamt of having a husband and children before she dies. Ellen’s illness has prevented long-term friendships with peers. The experience of being called a ‘freak’ following a prolonged period of coughing has forced Ellen to fabricate stories to prevent disclosure of the illness to her peers. Ellen’s family is quite over-protective, and has provided most of Ellen’s health care at home and during admissions to a paediatric hospital.

At the age of 16, Ellen was told her next admission would need to be at the local adult hospital; she had progressed through the hospital’s transitional care program to the adult health-care service, but she held reservations about an adult hospital admission.
Ellen’s first admission to an adult hospital was with a chest infection. She was very anxious about the admission, resisting until she was very ill. The adult hospital encouraged independence, and a high level of self-management was expected. Some two weeks into the admission, Ellen became aggressive and refused or delayed her medications, and became almost childlike in her dependency needs. The nurses were surprised and somewhat annoyed to see Ellen’s parents bathing and dressing her after they had insisted that she practise self-care. Comments from nursing and medical staff included that Ellen was manipulative, immature and lazy, that she cared little about her health, and that her parents perpetuated the situation. Later psychosocial assessment revealed that in fact Ellen was preoccupied with thoughts of her death as an adult and associated the adult hospital with the end of her life. Ellen preferred to have her parents provide total care, particularly when she was unwell, feared close relationships with adults – especially her peers – and had had thoughts of suicide using her own medication. Ellen felt more protected by assuming the behaviours of a younger developmental stage.

Many unresolved developmental conflicts are clearly evident in Ellen’s story: struggles with dependence and independence, identity issues, fears about intimacy and overprotection by understandably very anxious parents with significant enmeshment. Ellen’s parents preferred to maintain her dependence to protect her from growing up and having to take care of herself, knowing that she would only get sicker as she got older. Ellen’s father commented on the difficulties of caring for Ellen: ‘At least we have got her this far and there is no point building her up for a life that is not possible; she was fine until we brought her here.’ Ellen
confided that adult hospitals expected people to look after themselves, even when they didn’t look after themselves at home. She felt self-care was too difficult; and by remaining a child, she kept the family happy. Clearly, these views are understandable responses to an increasingly difficult situation for Ellen and her family, who refused to see a psychiatrist.

The regularity of the hospital admissions and outpatient clinic visits for Ellen and her family provided an opportunity for support, including the final acceptance of a referral to the adolescent consultancy team at the hospital. Subsequent comprehensive mental health assessment and a mental state exam identified high levels of anxiety, long-standing depression and suicidal ideation. Collaboration between the adolescent team clinical nurse consultant, the respiratory physician, the respiratory clinical nurse consultant and a community youth counsellor enabled treatment for depression and ongoing counselling. Ellen agreed to attend the hospital adolescent group room to mix with other young people with chronic illness, and to continue her schoolwork. Debriefing and group clinical supervision were also extremely valuable for the nurses caring for Ellen.

Ellen’s family members were her closest and strongest supports, and eventually, as the nurses came to understand the complexity of the parent–child relationship, they became supportive of both Ellen and her parents. Even more importantly, the nurses understood how to support the family as a unit, in what became a nurse–interdisciplinary team–family relationship. The role of the family working in collaboration with the nurses was invaluable to the psychosocial aspects of Ellen’s care. Completion of the tasks of adolescent development and the resolution of earlier
developmental conflicts for Ellen may not occur until she is well into her twenties or thirties, with total independent functioning most likely impossible. A family therapist was eventually accepted to explore feelings of guilt, grief and loss that had persisted for many years, preventing any sense of hope or normalising of family life.

Cases such as Ellen’s are complex, with the effects of the illness and treatment in conflict with the normal trajectory of psychosocial development and, clearly, the expectations of others. In such cases, health services may not have a right to decide what is right or wrong, given the terminal and severe disabling nature of many chronic illnesses, such as cystic fibrosis and cancer. Perhaps what families need from health staff is respect and acceptance for their predicament and the offer of supportive opportunities to meet current developmental needs rather than an assumption of what the young person should be able to achieve and an expectation of the role of parents.

Translation to practice

The developmental environment for many young people with chronic illness is dominated by hospital experiences. These experiences have the opportunity to inhibit or facilitate developmental task mastery. Through their ongoing contact with chronically ill young people and their families, nurses are influential in the health-care context of the young person’s developmental world, and they need a thorough understanding of adolescent psychosocial development and risk assessment. Moreover, nurses are perfectly placed to identify young people struggling with psychosocial development, whether represented by treatment adherence or
difficult and/or at-risk behaviours. However, given Ellen’s story, it is sometimes difficult for nurses to accept that, at times, psychosocial nursing interventions are most appropriately aimed at adding dignity and respect to a clinical situation, rather than promoting development.

**Intimacy versus isolation: Early adulthood (twenties and thirties) and the sick young adult**

Erikson’s sixth stage of psychosocial development, spanning the years of the twenties and thirties – the final stage for the focus of this discussion – involves the conflict of intimacy versus isolation (Erikson, 1968). The resolution of this stage is achieved with the establishment of a meaningful life, with a sense of connectedness to other people. Erikson describes this stage as finding oneself, yet also losing oneself in another person (Erikson, 1968). Young adults unable to resolve this conflict are less able to establish close relationships, often fearing rejection and isolating themselves from other people.

During this developmental period, young adults predominantly focus on seeking a career and developing intimate relationships with other people. The major developmental task at this stage is a psychological readiness and a commitment to mutual intimacy. This level of intimacy prepares the young adult for marriage or its alternatives to attain and retain individual identity within joint intimacy. If the young adult finds satisfying friendships, but is also able to achieve intimacy with another, the negative resolution of social isolation will be avoided. A negative resolution results in the young person being unable to establish close relationships,
increasing the risk of social problems and relationship difficulties (Erikson, 1968).

For some young people with chronic illness, the ability to have an intimate relationship while remaining largely physically dependent on parents or carers is extremely difficult – and for some it can be impossible. This situation may be a result of delayed emergence of adulthood identity as a consequence of prolonged poor self-esteem. Long-term poor self-esteem has been linked to the intractable challenge for some young adults experiencing poor health to find a comfortable identity and a place in society for themselves to emerge into adulthood (Luyckx et al., 2008). Luyckx and colleagues’ study, despite some limitations, identified this link as a precursor to adult depression and potentially other psychopathology.

Case Study 4.7 illustrates these challenges for Maria, and the challenge of response and/or helpful nursing care as she is admitted and readmitted to hospital several times in paediatric and then adult care.

**Case study 4.7**

**Maria – a young adult**

Maria was diagnosed with liver failure and subsequently underwent a liver transplant during her late teens. After a period of physical wellness, Maria is diagnosed with severe rejection of the new liver.

At the age of 22, Maria’s struggles with life highlight her experience of losing or delaying psychosocial developmental mastery. Maria found herself seeking the safety of more childlike ways of coping with the threat of illness and death. During each hospitalisation, Maria would behave almost like a child, rejecting any efforts by nurses to involve her in self-care; instead, she would
cry and ask for mother to care for her. Her mother, clearly distressed, longed to feel needed again and provide all care, including showers and feeding, as the only way she knew to support Maria.

This situation, or identity of being sick, suited Maria and her mother, who were now quite enmeshed. However, in hospital this became a problem as the health goals were for independent functioning and discharge as soon as Maria was medically stable. Nursing staff experienced the brunt of Maria’s and her mother’s emotions. Despite nursing efforts, Maria’s mental state became fragile, increasing her mother’s anxiety and bid to reject nursing assistance. This caused great distress among the nursing staff and frustrated bewilderment among the rest of the treating team.

During the final admission, Maria self-harmed, and deliberate attempts to sabotage her treatment while at home became clear. A youth health clinical nurse consultant was called to review care. Subsequent assessments of Maria’s psychosocial and mental state revealed long-standing depression and suicidal ideation rather than a long-standing diagnosis of adjustment disorder without treatment. Unrecognised mental illness is common among children and young people. It may be overlooked in medical treatment plans. Delay between onset of symptoms and treatment can potentially compromise psychosocial development and increase the risk of persistent mental illness in adulthood (Shapiro & Nguyen, 2010). The consultant liaison psychiatrist and the youth health clinical nurse consultant began to meet regularly with Maria and her mother, some antidepressant medication was commenced and counselling began, which was later continued in the community. A ‘care contract’ with Maria and her mother was agreed upon, which
took Maria’s dependence levels into account and moved forward with short- and long-term goals, leading to independent functioning and more confidence in self-care with the treatment regimens. It was a lengthy admission, but it was the last one for a long time.

Maria’s story highlights the risks and vulnerabilities of cumulative poor developmental task mastery or a regression in developmental mastery. Maria’s story begins during her recovery, with intermittent periods of organ rejection. During this recovery, Maria described how being better was the ‘greatest challenge of all’. She believed her difficulties had begun not when she was given her diagnosis or during treatment, but when she was considered medically well enough to return to her normal life. Maria felt her problems centred on a loss of who she was and on her inability to see a future of how to be in the world. She was not the person she had been before her health problems emerged, nor the heroic person who had survived a transplant, but another person who had to get back to normal – whatever ‘normal’ had now become.

When the severe rejection emerged, Maria felt more confident and was relieved to return to the identity of the sick person, receiving great support and respect from all around her. Once reluctantly ‘cured’ again – or rather, once the rejection was brought under control – Maria began to experience outbursts of temper. She punished herself with work, began to self-harm and refused to eat or to comply with the treatment regimen (medications, routine blood tests and so on). She was unable to share her feelings with anyone, as she thought they would see her as ungrateful for having receiving a liver from someone who had died and given her this gift of life. Over time, Maria began to develop a new identity and to move
on from a state of profound sadness to a desire for the ‘sick person identity’ to return. She asked, ‘Why does the system build you up to be a hero and survivor forever grateful to your donor while you are sick, without preparing you for the fall, when you get better?’

Little and colleagues (2002) define this time of identity confusion and relative safety with the illness as a state of liminality. ‘Liminality’ is a term that comes from cultural anthropology, and refers to a state of feeling ‘betwixt and between’ – rather like a social initiation to a new life. The state of liminality occurs when the individual feels they cannot identify with the person they were before the cancer, but rather feels a sense of fragile security in the identity of a sufferer (Little et al., 2002).

Persistent anxiety and depression – either because of unresolved developmental crises or associated with the loss of previously achieved developmental milestones – may well be the antecedents of adult psychopathology. A lifetime of chronic illness or a new diagnosis during the developmental period of adolescence or young adulthood can bring some similar and other unique challenges. Clearly, a thorough understanding of psychosocial developmental process and mastery, as well as the antecedents and recognition of mental illness in non-mental healthcare settings, is critical to ensure positive psychosocial and medical outcomes.

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<td>- How does psychosocial development influence the way in which children and young people respond to disruptions in health?</td>
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<td>- Outline the role of the interprofessional team in the care of young people with chronic illness both in the hospital and the</td>
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community.

- What is the relationship between responsive nursing practice and the psychosocial development of children and young people?
- What role does culture play in influencing the way in which children, young people and their families respond to disruptions in health?

Summary

- At the beginning of this book, we emphasised the growing concerns that exist about the growth in the number of Australian children suffering the burden of chronic illness. Three of the most common chronic conditions impacting Australian children and young people and the health care services supporting them are asthma, diabetes and cancer.

- Developmental disabilities, mental health disorders and eczema are other well-known chronic illnesses of childhood known to affect children’s broader health and social wellbeing, daily routines, behaviour and emotional adjustment (Morawska, Calam & Fraser, 2014).

- Like adults, children in hospital must adapt to stressful events related to illness, pain and contact with health professionals who are, in the main, strangers to them.

- Major stressors for children are separation, loss of control, injury and pain.
The way in which the child expresses anxiety and reacts to stress will depend on their growth, stage of development, maturity and repertoire of previous similar experiences.

In this chapter, we have used a framework of psychosocial development to present responses to illness experiences for children and young people. Respectful and therapeutic responses to these by nurses have been discussed:

> The welfare of the child and the family as they respond to disruptions in health is the key responsibility of paediatric nurses.

> Strategies that target responses to disruptions in health include family advocacy, disease prevention and health promotion, health teaching and, importantly, coordination of care.

> Cultural factors influence the way in which children, young people and their families respond to disruptions in health.

> Respectful health-care responses to cultural diversity include cultural awareness, acceptance and the provision of spiritual and cultural support.

**Learning activities**

4.1 Describe the major stress-related factors for a hospitalised child.

4.2 What responses to separation are expected? Discuss in relation to the developmental stage of the child.

4.3 Explain the potential reactions you will encounter in response to injury and pain:
4.4 What reactions might siblings have to the hospitalisation of their brother or sister?

4.5 What reactions might parents or caregivers have to the hospitalisation of their child?

4.6 What strategies can the paediatric nurse implement to ameliorate the effect of hospitalisation on the child and family? Include the siblings in your answer.

Further reading

The heavy burden of health problems experienced by Aboriginal and Torres Strait Islander people, particularly children and young people, can be overwhelming. The paediatric nurse may feel at a loss to know how their role can make a difference. We suggest the following website, as it provides examples of many successful initiatives that promise hope and resolution:

Australian Medical Association: [www.healthinfonet.ecu.edu.au/key-resources/bibliography?](http://www.healthinfonet.ecu.edu.au/key-resources/bibliography?&page=79&q=&q_exact=&q_author=&as_values_tagged_keyword=&sorter=year-DESC&health_topic%5B%5D=27&year_start=1840&year_end=2016&lid:]

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Svavarsdottir, EK & Orlygsdottir, B 2006, Comparison of health-related quality of life among 10- to 12-year-old children with chronic illnesses and healthy children: The parents’ perspective, Journal of School Nursing,


**Emotional response** – A reaction to an internal feeling, accompanied by physiological changes that may or may not be manifested outwardly

**Behavioural response** – A person’s actions or reactions in response to external or internal stimuli

**Chronic illness** – Any illness that persists over a long period and affects physical, emotional, intellectual and social functioning

**Hospitalisation** – A period of medical care in a hospital

**Psychosocial development** – The acquisition of social attitudes and skills, and the development of the personality from infancy through maturity

**Attachment theory** – The theory of the relationships between humans, particularly mother (or another primary caregiver) and child

**Cultural considerations** – The cultural factors that affect our experiences of the society in which we live and the events we experience
Research in the paediatric setting

Donna Waters

Learning objectives

In this chapter you will:

- Explore your understanding of the terms ‘research’, ‘evidence’ and ‘evidence-based practice’
- Be introduced to the core principles of human research ethics and research governance, and their application to paediatric research
- Develop your knowledge of techniques related to the development of research questions and the evaluation of evidence-based changes to practice
- Reflect on how you can use this knowledge in your work as a paediatric nurse to support evidence-based practice for children and young people, and encourage their partnership in research
Introduction

All people have a right to assume that health professionals are appropriately educated to focus their knowledge and skill on practice that is based on the best available evidence from research, and that this evidence informs the safety and quality of their care. Parents and carers of children and young people extend this assumption to health-care decisions made on behalf of those in their care. The tenet of using the best available evidence for decision-making is so self-evident and fundamental to health care that standards relating to quality, safety, research and evidence-based practice can be found in the professional registration standards of all health disciplines.

Research and evidence are intimately linked in nursing and health care, but each makes a slightly different contribution. We can broadly distinguish research as a systematic process for deriving new knowledge, and evidence as the knowledge that is produced and used. However, evidence from other sources is also used to inform health and treatment decisions – sometimes because good-quality evidence does not yet exist and sometimes because the evidence that does exist is not directly applicable to the context. The experience of the clinician or carer, the context of the health-care environment and the specific values and priorities of the child, family or community receiving care ultimately shape decisions about the quality of the evidence and how evidence is used. Sometimes these different sources of knowledge are categorised as external evidence (from research) and internal evidence (relating to the child, family, clinician or setting).

Evidence from good-quality and relevant research (which we will term ‘research evidence’) offers new ways to design and deliver care in paediatrics. Research evidence should always inform diagnostic, treatment
and care decisions and can offer insights into what is most important to children, young people and their families. Because research findings are constantly being redefined, research evidence can also bring new perspectives to maintaining wellbeing and assist with care and service-level decisions about paediatric workforce needs and priorities for research.

This chapter will discuss the particular challenges faced by researchers when they are conducting research with children and young people. We begin by clarifying the language of research and evidence as it relates to nursing. The tools of audit and benchmarking are discussed within the context of safety and quality in health care, and their relationship to research methods and the generation of clinical research questions is explored. We discuss special considerations for conducting ethical research with children and young people. Finally, we look at how children and young people can be supported to become more involved in research and gain influence in setting research priorities. But first read Case Study 5.1, to which we will refer later in the chapter.

**Case study 5.1**

**Benefit versus harm**

Cystic fibrosis (CF) is a common genetic condition in Australia, with approximately one in every four people carrying a mutation of the CF gene. The condition affects a number of organs, including the lungs, pancreas and liver. Because many children and young adults with CF also have pancreatic insufficiency, malnutrition and deficiencies of the fat-soluble vitamins (A, D, E and K) are common. Vitamin E deficiency has been associated with peripheral neuropathy, osteomalacia and inflammation.
You are a paediatric nurse working in the CF outpatient clinic and while you are weighing a 5-year-old boy, the parent shares that he has been approached by a member of a research team (a gastroenterologist) who is conducting a study to look at vitamin E and peripheral nerve dysfunction in children with CF. The study information sheet and consent form the parent shows you state that the child will be required to undergo nerve conduction studies and electromyography on two occasions over the next 12 months, as part of a randomised controlled trial of high-dose vitamin E supplementation.

The parent asks, ‘What is the benefit of this research to my child?’ and ‘Would you allow your child to be part of this study?’ How would you answer?

**What is research?**

In this chapter, we define terms used in quality and safety management, health research and research ethics. Somewhat confusingly in research, you will find that people use the same words in different ways, depending on their disciplinary training or geographical background. For example, the term ‘knowledge translation’ is used extensively in the United States and Canada to describe the process of moving what we have learned from research through to application in health-care and practice settings. But this process is also referred to as knowledge transfer, research/knowledge diffusion and dissemination. In the United Kingdom and Europe, the term ‘evidence implementation’ includes research utilisation and evidence transfer. Collectively, these terms refer to a process that more recently has
been branded as ‘implementation science’, or the study of approaches and methods used for evidence transfer or knowledge translation.

**Generating knowledge through research**

Research is a systematic and rigorous process used for the generation of new knowledge. Researchers choose from a range of methodological approaches and select methods to find the answer to a focused and answerable research question. In general, an answerable question will define a population, person or problem; an intervention or issue; and a comparison group (if used). It will also have clearly defined outcomes. The timeframe or type of study may also be included. It is common to see research questions written in this PICO(T) format (see, for example, Boluyt et al., 2012 and Jarrett et al., 2015).

The systematic and rigorous process of research proceeds through a series of steps that are relatively standard, but what happens at each step will vary, depending on the theoretical and methodological approach chosen by the researcher. Theories offer a useful scaffold for the conduct of research as they guide the researcher in decisions about the assumptions underlying the research, and what is accepted as valid and reliable evidence of these assumptions, and therefore inform the context of the investigation (the methodology) and the way evidence or data is gathered (the method).

The main steps of the research process are:

- Define the problem.
- Pose an answerable research question.
- Search the literature to see what is already known.
- Develop a research design and choose an appropriate method.
Imagine that you are following the steps of the research process to answer a question about effective post-operative pain management in infants. Then think about this same question applied to an adult post-operative setting. The difference in populations will likely influence your choice of theoretical perspective and application of the methodology and method. At each step, you will need to think in a different way about how to answer this question, considering the types of surgery children and adults have, how they are managed post-operatively, the medications that are used for pain (the intervention), how pain is measured (the outcome) and so on. The process for gaining ethics approval and consent would also be different, but the steps of the research process remain the same. Before we move on, let’s be sure we have a good grasp of research language and how the words ‘research’ and ‘evidence’ relate to each other.

**What is evidence-based practice?**

We have defined research as a systematic and rigorous process for deriving new knowledge, and evidence as the knowledge that is produced from research. We have also acknowledged the contribution of evidence from internal sources to health and treatment decisions. In reality, there are many research questions that simply have not yet been answered, and many for which research exists but may not be of sufficient quality to allow us to confidently answer the question. These are important issues in

- Gain ethical approval and funding (if required).
- Collect data to conduct the study.
- Analyse the data to answer the question.
- Disseminate (or transfer) the results.
the generation of evidence from research. You will find that the evidence derived directly from research may also be called research evidence or external evidence.

Possibilities for using evidence from research can also be impacted from the supply or demand side (Figure 5.1). For example, good-quality research may exist to answer our question, but the health-care environment may prevent us from acting upon the evidence. This could occur when a health service has insufficient staffing or other resources to change practice, or is unable to offer a new treatment because of cost and is therefore unable to deliver. Other possibilities are that the child, young person or family simply does not accept the treatment choices offered by the evidence, or that clinicians and other stakeholders are unable to support a practice change (lack of demand). Figure 5.1 illustrates that the success of using evidence in practice relies both on the generation of evidence (the research supply side) and on delivery and demand.

Figure 5.1 Possibilities for generating and using research evidence

One less palatable possibility should be mentioned. This is where good-quality evidence from research exists and is well disseminated and possible to implement, but for whatever reason a health professional chooses to ignore it. An example of this occurred in Bristol in the early 1990s, when a consultant anaesthetist exposed very poor outcomes from
cardiac surgery at the Bristol Royal Infirmary (Savulescu, 2002). In this example, surgeons continued to perform cardiac procedures on children despite clear evidence that the overall mortality rate was almost double that reported by other paediatric surgical outcome studies at the time. The hospital had refused requests to investigate three paediatric surgeons who, six years later, were found guilty of serious professional misconduct. The actions of this so-called whistleblower not only significantly improved the subsequent mortality rates of children having heart surgery in Bristol by ensuring best-practice surgical procedures were implemented, but also established basic principles and practices for what is now known as clinical governance across the United Kingdom, Australia and New Zealand.

**Evidence as contextualised knowledge**

Earlier, we described evidence as contextualised knowledge from research and other sources, and Figure 5.1 showed that a number of possibilities exist for generating and using evidence. But evidence also comes from many other internal sources, the most important of which is the intrinsic cultural and ethical values and preferences of children, young people and their families. Rather than ignoring internal evidence, synthesis of this knowledge with external evidence from research is what permits us to deliver personalised, high-quality and safe care to children and young people in a contextually appropriate way. This is the basis of person/patient or family-centred care.

It is well known that recommendations for evidence-based practice are made with reference to a series of steps (see Table 5.1). Some of these steps are consistent with the research process, but there is a major area of divergence when it comes to the ‘doing’ of research or the ‘using’ of
evidence. The evidence-based practitioner derives questions directly from their practice. How often have you had a thought like, ‘This child keeps pulling their bandages off – I wonder whether there is another dressing I could use to keep the wound covered?’ Clearly you cannot instantly set up a randomised controlled trial to test two different types of dressing to help you answer this question; however, you can focus your question (ask), conduct a search of the research literature (access), determine the quality and appropriateness of the literature you find (appraise), answer your question and apply your new knowledge to your practice, and then assess or evaluate (audit) whether the change has made a difference. Sometimes you see the five ‘As’ of evidence-based practice written as assess the problem or patient, ask the question, acquire the evidence, appraise it, then apply it to practice.

Table 5.1 The research process and evidence-based practice

<table>
<thead>
<tr>
<th>A researcher</th>
<th>An evidence-based practitioner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asks a research question</td>
<td>Asks a practice question</td>
</tr>
<tr>
<td>Conducts a review of literature</td>
<td>Conducts a review of literature</td>
</tr>
<tr>
<td>Develops a research design</td>
<td>Determines the quality of evidence from the literature</td>
</tr>
<tr>
<td>Determines the best method to use</td>
<td>Summarises the results</td>
</tr>
<tr>
<td>Gains ethical approval and funding (if required)</td>
<td>Answers the question</td>
</tr>
<tr>
<td>Conducts the research study</td>
<td>Applies results or implements practice changes</td>
</tr>
</tbody>
</table>
Research translation

We know that health care is not delivered in a vacuum, and it is usually in the implementation stage of evidence-based practice that contextualised knowledge from other sources most significantly impacts the process. Every health-care encounter will be slightly different because every child and family are different – as are competing factors, barriers and environmental influences. Similarly, a young person might exercise their right to choose to ignore your advice, regardless of how strong the evidence might be for a particular recommendation. The complex interplay of research evidence with clinician contribution (or lack of contribution) and patient and family preference takes place within the environment of a clinic, hospital, home or community setting – all of which are moderated by economic, environmental, social and political contexts.

While nurses generally accept that evidence-based practice is a positive practice strategy, basing practice on evidence is definitely not easy. In a systematic review designed to understand and measure how long it takes before findings from health research are converted to patient benefit (a process called translation), Morris, Wooding and Grant (2011) concluded that while a number of studies had coincidentally landed on the answer of 17 years, the use of different approaches and endpoint measures in the 23 studies included in their review made it difficult to arrive at a definitive answer. However, this estimate has not substantially changed in
the 10 years since the US Agency for Healthcare Research and Quality (AHRQ) proposed that ‘it may take as long as one or two decades for original research to be put into routine clinical practice’ (AHRQ, 2001: 1). Considering the many internal and external factors influencing the implementation of evidence in paediatrics, we clearly have a lot of work to do in speeding up this translation pathway.

**Related techniques**

Audit and benchmarking are specific techniques for capturing, comparing and contrasting data. Used extensively within the context of safety and quality, they are effective tools for the generation of clinical research questions and for evaluating the impact of evidence-based practice changes. Before continuing, let’s look at the example of safety and quality in health care.

The adoption of a consistent and independent approach to the measurement of outcomes – called indicators in this example – means that patient safety and the quality of health-care outcomes can be monitored and observed for trends over time. Further, health professionals are alerted to possible system or process compromises when upward or downward trends occur, such as increasing rates of central venous line (CVL) infection or incidents of violence.

**Example: Safety and quality in health care**

Safe and high-quality health care is an expectation of all Australians, but is not always achieved. The Australian Commission on Safety and Quality in Healthcare (ACSQH) was established in 2006 to lead and coordinate national improvements
in safety and quality. Adopting a framework based on core principles for the delivery of care that is consumer-centred, driven by information and organised for safety, the commission has developed 10 national standards for health services – the National Safety and Quality Health Service (NSQHS) Standards (ACSQH, 2012) – for the purpose of improving the quality of health care in Australia. These standards offer a nationally consistent approach to measuring quality and safety, and have formed a base for the accreditation of health services in Australia since 2011.

The process of routinely and consistently measuring and collecting health outcome data, and comparing it against explicit criteria for the purpose of making improvements, is called clinical audit. Audit data offer the opportunity to compare performance against best-practice standards. This compare and contrast process is called benchmarking – where performances on a range of measurable quality indicators are not only captured and compared across other similar health services, but can also be measured against the achievement of an aspirational target, such as aiming for zero CVL infections per month. Benchmarking very quickly enables the identification of both excellence and gaps in performance, and is a strong driver of health research. The next question most health professionals would ask when looking at benchmarking data is *why* one place is performing better than another on a particular measure.

In the previous example of cardiac surgery at the Bristol Infirmary, the anaesthetist used audit techniques to document observed surgical outcomes and then compared these (benchmarked) against results for similar operations at other paediatric surgical centres to prove that quality was compromised (Savulescu, 2002).
Reflection points 5.1

- As with any new language or jargon, research language can be intimidating and confusing for someone who is not used to it. Do you believe nurse educators and academics are adequately preparing paediatric nurses to use research?

- ‘Research’ and ‘evidence’ are terms that are often used interchangeably, but in fact their meanings are perceptibly different. Do you think the careless use of these words has had any impact on how nurses working in neonatal and paediatric care settings feel about research?

- Evidence can be derived from research (external evidence) or from other sources (internal evidence). What impact might the geographical location, setting or health-care environment have on your ability to use evidence in your practice?

- Evidence-based practice is usually presented as a series of five steps, consisting of asking a question, accessing evidence, appraising the quality of the evidence, applying results in practice, and assessing or evaluating the effect of the change. Which of these five steps do you think would be the most challenging in paediatric nursing practice and why?

- The successful and timely translation of research into practice remains challenging, but can be accelerated through the identification of practice gaps. Have you seen quality and safety reports from your own workplace? Have you asked ‘why’ questions about the data you have seen – and have you then
Researching with children and young people

Before we begin this section, we return again to the language of research. As health professionals, we are privileged to have the opportunity to conduct research with the children, young people, families and carers with whom we come into contact. But this is a privilege, not a right. You will sometimes see or hear researchers refer to research ‘in’ people, or research ‘on’ people, but how can this be? No researcher, however esteemed, has the right to assume ownership of the rights of another adult or child. The ethics of research include the principles of respect for people and their rights, beneficence and justice. Research ethics therefore presume that we conduct research ‘with’ people and not ‘on’ them. At a time when we know that children and young people in our own country and around the world are still being denied basic human rights, it is important to remember that the principles of research and research governance founded in the Nuremburg Code (see the section on research ethics below) are intended to be applied fully and globally.

Human research and ethics

Human research includes any research that is ‘conducted with or about people, or their data or tissue’ (NHMRC, 2007a: 3). Human research therefore includes everything from the use of personal information or
secondary data, observation, questionnaires, interviews and surveys through to the collection of body fluids and tissues (including exhaled breath) and psychological, physiological and medical interventions or tests. The Royal Liverpool Children’s Inquiry into the Alder Hey Hospital (Dewar & Boddington, 2004), for example, highlighted many areas of confusion around consent for post-mortem research, and the storage and retention of children’s organs and tissue for education and research purposes.

While the process of research is largely the same whenever and wherever it is conducted, the paediatric setting presents some specific challenges related to the ethical conduct of human research. Children and young people have a range of developmental capacities for understanding their involvement in health-care decisions and research, and are recognised as a vulnerable group under Australian ethics guidelines. Further, research with children and young people often raises many questions about the consent process and the possibility of conflicting values when parents or carers are giving consent for research participation on behalf of children and young people in their care. This is why offering rewards for participation in paediatric research is rarely regarded as appropriate during consent, and why rewards should never be offered to prevent children withdrawing from a study (RACP, 2008).

The future will present even greater challenges for human research ethics as personal data are increasingly collected, shared and stored through data registries and social media networks, and biological samples are progressively accrued through storage banks (bio-banks). Dried blood samples from pre-natal and newborn screening programs are an example. Further, improved technologies increasingly permit residual blood or tissue obtained from clinical procedures to be stored for long periods,
offering enormous potential for future research, genomics and personalised medicine.

While the Australian National Statement on Ethical Conduct in Human Research (NHMRC, 2007a) provides guidance to human research ethics committees and others, access to specimens stored in human biobanks will continue to raise important ethical questions into the future. It is increasingly common for research consents to include ‘opting in’, which gives implied consent to use data or samples for research conducted into the indefinite future. ‘Opting out’ involves a person being sufficiently informed to understand that they can actively refuse permission for their sample to be stored and/or used for further research. There remains a great deal of speculation about appropriate opt-in and opt-out procedures with children and young people, and parents are often unaware of their rights and responsibilities around consenting or opting out (Giesbertz, Bredenoord & Delden, 2012). Mechanisms for allowing the young person’s autonomous affirmation of consent when they either have developmental capacity or reach the statutory age of consent need to be built into the research design.

**Research ethics**

The ethics of human research are based on three fundamental principles, which broadly attest that any risks from the research will be outweighed by the contribution of the research to improving health and health care, and that the dignity, privacy and wellbeing of the research participant will be protected at all times. It is difficult to discuss health ethics without reference to history. The Nuremberg Trials were an investigation into experiments performed in Nazi Germany during World War II, and became a pivotal point for the development of a universal written code of
medical ethics known as the Nuremberg Code of 1947. Interestingly, the first of the 10 principles in the Code relates to the giving of voluntary consent by the human subject. While we now refer to this as the principle of autonomy, at the time, the Code technically precluded children or any other person unable to give direct voluntary consent from participation in research (Davidson & O’Bien, 2009).

The 1964 Declaration of Helsinki attempted to reflect the major principles of the Nuremberg Code within the specific context of biomedical research. Revised several times over the intervening 50 years, the most recent Declaration is available online. A range of international organisations have also developed and published guidelines for the ethical conduct of health and biomedical research, including the Council for International Organisations of Medical Sciences (CIOMS) and the World Health Organization (WHO). Australian guidelines have been jointly developed by the National Health and Medical Research Council (NHMRC), the Australian Research Council (ARC) and the Australian Vice-Chancellors’ Committee (AVCC). These are published as the National Statement on Ethical Conduct in Human Research 2007 (or National Statement), and are regularly updated (NHMRC, 2007a). All guidelines developed since the Nuremberg Code specifically contain sections relating to research with vulnerable groups, including children and young people.

Another pivotal point in the history of human research ethics was the release of the Belmont Report, commissioned by the US Congress in 1974. In an attempt to further clarify and articulate principles from the Nuremberg Code and Declaration of Helsinki, the report describes the distinction between what we today call ‘basic’ research (laboratory or benchtop experimentation with biological specimens or animal models) and clinical or ‘applied’ research conducted with people.
There is documentary evidence dating back to the nineteenth century showing that children in paediatric hospitals and orphanages were being researched ‘on’. Certainly children and young people were among those experimented on under the guise of medical research in Nazi Germany. In another example that occurred during the 1960s, parents of intellectually disabled children who were institutionalised at the Willowbrook School in New York were forced to consent to their children being infected with hepatitis during vaccine development experiments (Link, 2005).

Core principles of research ethics

The National Statement organises the discussion of ethical values in research around the central principle of respect for human beings. While this guideline maintains the three fundamental ethical principles of research contained in the Belmont Report (respect for persons, beneficence and justice), guidance for research merit and integrity is also included. The broader ethical values of altruism, contribution to societal or community goals, respect for cultural diversity and nationally specific values are included in a companion document to the National Statement, entitled Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (NHMRC, 2003). A further resource for Aboriginal and Torres Strait Islander communities is Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics (NHMRC, 2005). This aims to support shared decisions with researchers about values, priorities and participation for mutual benefit in health research.

Research merit and integrity
The principles of respect for persons, beneficence and justice exist under the assumption that any research of poor scientific merit will be unethical. Any child, young person or adult has a right to expect that before their participation in a study is considered, the proposed research has a clear and answerable aim or question, is informed by current research evidence, uses an appropriate design and method, can actually be undertaken and completed and the results reported (remember the steps of the research process), and will be conducted or supervised by researchers with appropriate paediatric experience and training within a safe and appropriately resourced environment. The role of human research ethics committees (HRECs) is discussed later, but for now we can say that it is also expected that any research involving humans will be reviewed by the HREC of the institution at which the study will be conducted. The ethics committee has a role in monitoring the research governance processes.

HRECs require sufficient evidence of the scientific merit of a study for a decision to be made about the balance of actual or potential risks for the participant against the stated aims of the research. There is an expectation that the proposal will demonstrate that the research will be sufficiently feasible (that it can actually be completed) and scoped (able to produce a reliable result) in order to make a meaningful contribution to knowledge. The Australian Code for the Responsible Conduct of Research (NHMRC, 2007b) explains the specific role of institutions and researchers in promoting research integrity, and offers advice on managing departures from best practice, such as research misconduct.

With regard to specific considerations for children and young people, research governance principles focus on whether the research method is appropriate for the age and developmental maturity of the intended sample of children, and whether the researchers have the appropriate training and experience to work with children and young people within the context of
their research question. An important aspect of the research design will be to describe how children and young people will be approached for participation (recruited to the study); whether the facility or environment in which the study is to be conducted is appropriate to their needs; any potential impact on the child’s family or community, such as may occur in school-based research; and a clear description of how researchers will judge the capacity of potential participants and their families to understand the project and its risks, and give their consent to participate.

**Autonomy and respect**

The principle of respect recognises that individuals have intrinsic human value, and therefore have the right to make autonomous or collective decisions about participation in research. Respect includes valuing the interactions human beings have with each other through common beliefs, customs, perceptions and culture, as well as individual rights to privacy and confidentiality. For children and young people, these interactions extend to relationships with parents and carers, and include the responsibilities of parents and carers to protect and support children and young people with diminished developmental capacity to make autonomous decisions.

In addition to ethical considerations applicable to all humans, the National Statement identifies specific participants who are considered vulnerable within the context of research and for whom studies requiring participation in research must be reviewed by a HREC. Vulnerable participants include pregnant girls and women and the human foetus; children and young people; people in dependent or unequal relationships; people who are highly dependent on medical care and who may be unable to give consent; people with a cognitive impairment, intellectual disability
or mental illness; people who may be involved in illegal activities; Aboriginal and Torres Strait Islander peoples; and people living in other countries (NHMRC, 2007a: 46). It should be noted that, in addition being named as a vulnerable group in their own right, children and young people may be represented in any or all of these other vulnerable groups.

The National Statement respects the different developmental capabilities of children and young people to be involved in decisions about participation in research in two ways: first, the guidelines do not specify the exact ages at which consent may or may not be given; and second, the guidelines are flexible about decisions regarding a child’s level of maturity and subsequent capacity to understand the complexities of the proposed research. Apart from suggesting responsiveness to a child’s developmental capacity to understand their involvement in research, the National Statement proposes that ‘even young children … should be engaged at their level in discussion about the research and its likely outcomes’ (NHMRC, 2007a: 50). Therefore, while an infant clearly cannot participate in this discussion, a young child may be capable of understanding aspects of the research sufficient to ask questions – for example, ‘Will it hurt?’ – and, particularly in later childhood, may be deemed mature enough to give fully informed and free consent.

**Consent in paediatric research**

Obtaining consent for participation in research is central to respect for individuals. Free and informed consent implies a voluntary decision that is not influenced by coercion, pressure or inducement (Davidson & O’Brien, 2009). When a child is unable to give free and informed consent, parents or guardians are asked to make a judgement based on their interpretation of the child’s best interests and the level of risk to be endured for the sake
of others. Parents and children are also both at risk of the sometimes subtle coercion that may exist when a favourite nurse or doctor asks them to join a research project.

The various Australian states and territories all have specific legislation around the age at which minors are deemed to have capacity to consent to treatment (RACP, 2008), but this may not apply directly to participation in a research project. Paediatric research participants can be grouped into three broad categories for the discussion of consent for participation in research; however, as the National Statement suggests, it is inappropriate to define individual maturity by age, or to assume that the complexity of the research is beyond the understanding of the child. It is clear that infants are unable to give free and informed consent, so only parental/guardian consent is required. Children may have the capacity to understand the nature of the research and may consent to participate. However, children are still considered vulnerable, and their research participation will require the additional consent of one parent. Finally, mature children and young people capable of understanding the risks and benefits of their participation in research may give sole consent and parental consent may be waived.

In general, consent from children and young people should be gained in the following circumstances:

- For a child or young person, consent may be obtained when they have the capacity to make the decision with additional consent from either one parent, guardian or primary caregiver (or any organisation or person required by law).

- For a young person, sole consent may be given as long as the ethics review body is satisfied that the young person is mature enough to understand the relevant information; the research involves no more
than a low risk; and the research will be of benefit to the group of young people to which the participant belongs; or the young person is estranged or separated from parents or guardian; or it would be contrary to the best interests of the young person to seek parental consent. (NHMRC, 2007a: 50)

Exceptions to these general rules occur when conditions are contrary to state or territory legislation, where an ethical review body decides that the nature of the research requires the consent of both parents, or where vulnerabilities might exist in aspects of the life of a young person that are unrelated to their understanding of consent. For example, this might include developmental aspects of accepting risk and burden for moral or altruistic reasons, social immaturity or homelessness. Researchers must therefore take the capacity of each individual child or young person into consideration during the process of consent. The project and all risks should be explained in developmentally appropriate language and with consideration to what is important and valued by the child and their family. This respect for children and young people is fundamental to recognising the intrinsic value of human beings and their capacity to make autonomous decisions about participation in research, including rights to privacy and confidentiality. These basic rights are declared in the World Medical Assembly’s Ottawa Declaration on the Rights of the Child to Health Care, adopted in 1998 and amended in 2009 (WMA, 2009).

In addition to involvement in health and medical research, children and young people also have significant representation in educational research. You may already be aware that the National Statement has a provision that permits parents to give standing parental consent to research conducted within the educational setting. Schools may, for example, seek standing parental consent at the beginning of a school year
for their child’s involvement in research, provided that the research is deemed to be of benefit to children of a similar age and does not compromise learning or involve disclosure of sensitive personal or family relationship and/or potentially identifiable information.

You may also see the word ‘assent’ used in discussions about the participation of children and young people in research. Assent relates to a child agreeing to participate in research without the giving of free and informed consent. It has certainly happened that parents have given consent on behalf of a child who has refused to assent. In this case, it is clearly inappropriate to proceed. In general, both parental and child assent are required for participation in research – except, of course, in the case of infants or where clear possibilities of benefit from the research are demonstrated to the parent. This leads to the next of the three fundamental ethical principles: beneficence, which attests that any risks from the research will be outweighed by the contribution of the research to improvements in health and health care.

**Beneficence in paediatric research**

The ethical principle of beneficence relates to balancing the risk of benefit and harm in research. In general, researchers are responsible for ensuring that their research design minimises any actual or potential risk to participants. Where there are minimal or no likely direct benefits to research participants, the researcher must demonstrate that the risk of participation is lower than would be ethically acceptable when there are likely benefits (NHMRC, 2007a).

Beneficence is also demonstrated by participants of a research study when they undertake an estimate of their personal level of risk against the risk of not contributing towards improvements in health or health care that
may result from the research. Non-maleficence (or doing no harm) is another term used in the discussion of benefit versus harm in research. The idea of potential harm to a research participant is balanced by the notion that any perceived or real harm or risk suffered will be outweighed or exceeded by the benefit accrued by the individual on behalf of the greater good. In the context of research ethics, a risk is anything that has the potential for harm, discomfort or inconvenience.

Discomfort is a less serious form of risk that can also be physical or psychological, and can be perceived or real. For example, when conducting research with young people being interviewed about their lived experience of being diagnosed with epilepsy, a young person might become psychologically distressed by or uncomfortable about discussing their experiences, but they are unlikely to suffer long-term harm as a result of sharing this information with the researcher. There is usually some level of inconvenience associated with participation in research. This is especially relevant to parents or carers of children and young people who may need to take time away from work or family, or may incur financial or emotional costs connected with their child’s participation in research, such as for travel, meeting with researchers and completing consent and testing procedures. In relation to the previous example, it may be more appropriate for the researcher to consider that they should travel to conduct in-depth interviews in the young person’s own home, or in a neutral environment close to psychological support and counselling if needed, rather than expecting the young person to come to them.

A concept related to ensuring that the research design provides the best possible approach to maintaining the emotional, psychological and physical safety of participants is that of maintaining the best interests of the child or young person. This includes many of the principles we have already discussed, such as respecting a child’s right to refuse to participate,
the capacity of the child to understand the research and give consent, and provision for refusal to be overridden by the parent’s judgement if this is deemed to be in the best interests of the child or young person. An example clearly demonstrating the failure of researchers to maintain the best interests of children comes from the well-known 1998 study published by Andrew Wakefield in the prestigious medical journal *The Lancet*. Now proven to be fraudulent, this study claimed a causative association between the measles, mumps and rubella (MMR) vaccine, autism and bowel disease (Godlee, Smith & Marcovitch, 2011). This prompted a worldwide vaccination scare, and it was seven years before the study was fully investigated and 12 years before it was formally retracted. Meanwhile, childhood vaccination rates plummeted in the United Kingdom, with measles being declared endemic in 2008. Twenty years after this study, child immunisation rates in the United Kingdom remain below the level determined by the World Health Organization as necessary to achieve herd immunity.

Risk is the potential for harm, discomfort or inconvenience to occur. It is generally accepted that the level of risk to which children and young people are exposed through participation in research should be lower than that for adult research participants. However, the assessment of risk is different for everyone, and it is important to remember that risk can be actual or perceived. The assessment of risk is also about weighing the relative probabilities associated with the likelihood of risk occurring, and the severity or extent of harm that may result if the risk occurs (see Figure 5.2). Knowing the probability and severity of risk is one of the ways in which children, young people and their parents or guardians can judge the extent to which they are at risk from participating in research, and researchers and ethics committees can determine how these risks might be minimised and managed.
Human research ethics committees will generally allocate research to a category of risk to determine the level of ethical review required. Research of ‘low or negligible risk’ refers to types of research in which the actual or perceived risk is gauged to be no greater than discomfort (low) or inconvenience (negligible). In the United States, the term ‘minimal risk’ is used to denote risk that is no greater than what a child might expect to encounter in everyday life – a child might expect to fall off a bike, for example. However, as Davidson and O’Brien (2009) suggest, a single blood test on a calm infant performed by an experienced venepuncturist using a topical anaesthetic can present an entirely different level of risk if the infant becomes distressed.

Now let’s revisit Case Study 5.1 to determine how you might answer the questions posed by the parent of your young patient with CF. To reiterate, you are a paediatric nurse working in the CF outpatient’s clinic and while you are weighing a 5-year-old boy, the parent shares that they have been approached by a member of a research team (a gastroenterologist) who is conducting a study to look at vitamin E and peripheral nerve dysfunction in children with CF. The patient information sheet and consent form the parent shows you state that the child will be required to undergo nerve conduction studies and electromyography on two occasions over the next 12 months, as part of a randomised controlled
trial of high-dose vitamin E supplementation. The parent has asked, ‘What is the benefit of this research to my child?’ In brackets after each point below are some ethical principles to consider.

- The child and parent have a five-year relationship with a member of the research team, who is also the child’s gastroenterologist. (Coercion?)
- The child may be randomised to either the treatment (vitamin E) or placebo (no treatment) arm of the randomised controlled trial. (Beneficence and autonomy?)
- Is the child willing to participate in the study, undertake the testing and take more medication? (Assent and consent?)
- Nerve conduction studies can be painful. (Potential for harm?)
- The child and/or parent will need to make at least two extra trips to the hospital for testing, and attend the pharmacy to pick up the medication. (Inconvenience and cost?)
- The child has a chronic childhood disease and may have already participated in many paediatric research studies during their five years of life. (Justice?)

We will return to your considered response to the parent after we look at the ethical principle of justice.

**Justice in paediatric research**

Justice is an integral part of all ethical research because this principle is concerned with fairness and equity. Consideration of justice starts with the experience of researchers within the paediatric setting, and their ability to
focus the research question and design the study to be consistent with the way children and young people feel comfortable in the world. For example, has the research been designed to maximise chances of participation? Is the process of recruitment fair? Will all children and young people benefit equally from the results? We see examples of research inequity and injustice frequently in the Australian context. Paediatric participation in research translated to care and treatment in large metropolitan teaching hospitals and clinics may remain largely unknown and unseen in smaller rural and remote facilities. There are many subgroups within the Australian paediatric population that we know to be excluded from both participation in, and the translation of, the benefits of research and new discoveries.

Fairness also relates to the burden of the research, as previously discussed. For example, is the inconvenience caused to children and their parents reasonable compared with the actual benefit that an individual child might gain? Is the participation of children and young people indispensable to the conduct of the research, or could the questions be answered by the recruitment of adult participants only? Do new biological samples need to be obtained or could the same question be answered using stored human bio specimens? Within the context of autonomy and beneficence, the principle of justice is deeply embedded in decisions around whether it is justifiable to involve children and young people in research when they may not benefit directly, particularly when considering the issue of maturity to give free and informed consent and the age-related development of altruism (Eisenberg et al., 1991). Now let’s return to our case study and the question of whether you would allow your child to be part of the vitamin E study.

One way to answer this question would be to determine what might constitute an acceptable level of risk for the child, given their age and
diagnosis. As an informed, research-aware paediatric nurse, your ‘thought bubble’ might look something like the one shown in Figure 5.3.

**Figure 5.3** Formulating an answer to a question about participation in research

- The child's gastroenterologist is an active and experienced researcher who has already contributed significant research evidence to improving the care of children with CF
- The study has been approved by a Human Research Ethics Committee; the Information Sheet and Consent Form clearly state the risks (discomfort) of the nerve conduction studies, describe the randomisation and the possibility that the child may be allocated to the placebo arm of the trial
- High dose Vitamin E is unlikely to be harmful to this child if he is allocated to the treatment arm of the trial
- The child is likely to experience some discomfort during the testing and the parent will be inconvenienced by two additional trips to the hospital (unless the visits can coincide with routine clinic visits)
- The results of the research are likely to be influential in the future management of fat-soluble vitamin deficiency in CF and if findings are positive, may potentially reduce or prevent the effects of future peripheral nerve dysfunction

**Reflection points 5.2**

- Recognition of autonomy and respect in human research ethics values the intrinsic rights of a human being to hold individual and collective beliefs, perceptions, customs and cultural norms. These principles also imply that the design and scope of paediatric research will respect the individual capacity of children and young people to make their own decisions. What steps can you take to ensure that clinician/patient/family relationships between health professionals, parents, children and young people do not impact on their consent decisions for participation in research?
- Research that exposes a child’s genome for the early identification and treatment of disease may or may not have immediate relevance to their current or future health, but has
many potential longer-term impacts. These may be significant for the child, their family and other blood relatives in terms of options for reproductive or treatment decisions, employment and susceptibility to disease, and therefore life or health insurance. There is also the possibility of creating unexpected relationship stress around paternity or family-planning issues. What other potential risks of genetic research can you identify for the child or young person and their family?

- In research ethics, the principle of justice requires that any potential benefits or burdens from the research are distributed fairly among all age, gender, social, economic, cultural and ethnic groups. Think about research in which you have been involved, or with which you are familiar, and consider whether this research was ‘just’.

Research monitoring and participation

In this final section of the chapter, we will look at the role and function of HRECs in monitoring ethics and research governance in paediatric research. We will also discuss how you can use your knowledge about research, evidence and research ethics to support evidence-based practice in paediatric nursing, and encourage greater participation and partnership with children and young people in Australian paediatric research.

Human research ethics committees

The ethical review of research conducted within institutions is assessed relative to the level of risk. The National Statement (NHMRC, 2007a)
recommends that any research that is perceived to have anything more than a low level of risk must be reviewed by an appropriately constituted HREC. As discussed above, low risk is defined as the actual or perceived risk being no greater than a level of discomfort and negligible risk is described as ‘research in which there is no foreseeable risk of harm or discomfort’ (NHMRC, 2007a: 13). It is recognised, however, that any participation in research is likely to cause some inconvenience. Many institutions have provisions for the approval or exemption of low and negligible-risk research, often through the formation of a sub-committee of the HREC.

The role of the institutional HREC is to give guidance to the institution and its researchers through a judgement about whether the proposed research meets the requirements of the National Statement. No research that is judged to present any risk to participants may commence until approval from the HREC is received, and often full funding of the research is withheld until evidence of HREC permission is presented. Research participants must be provided with direct contact information for an independent HREC representative if they wish to complain, and annual declarations verifying the continued safe and ethical conduct of the research are required. The National Statement (NHMRC, 2007a) gives guidance for processes of research governance and ethical review, including recommendations for the operation and membership of institutional HRECs. In other words, the HREC helps researchers, reviewers and funders of research to identify their responsibility and accountability for ethical research, and provides criteria for managing conflicts of interest, handling complaints, and reviewing and monitoring the ethics, quality and safety of research projects.

As we have already identified, the National Statement on Ethical Conduct in Human Research (NHMRC, 2007a) and the Australian Code
for the Responsible Conduct of Research (NHMRC, 2007b) collectively dictate processes for research governance that enable institutional HRECs to undertake standardised ethical review. The National Statement outlines procedures for the establishment of HRECs, including their resourcing, composition and procedures. At a minimum, membership of HRECs must include two laypersons (a man and a woman) described as having no direct affiliation with the institution and not currently engaged in ‘medical, scientific, legal or academic work’ (NHMRC, 2007b: 72).

**Contribution to research**

We began the section on researching with children and young people by encouraging you to think about children and young people as partners in research. While HRECs have long been mandated to include representative laypersons in their membership, it has taken research teams and funding bodies much longer to organise systems and processes for consulting and partnering with the groups or members with whom they are researching. There is still much work to be done to ensure fair adult representation in research, and even more to promote the representation and active involvement of children and young people in prioritising research topics and directing funding.

Research engagement with children and young people can be facilitated by ward-based ‘patient committees’ or during external events such as conferences and camp activities associated with support groups and charities – for example, Children with Disability Australia, CanTeen, the Raising Children Network, Asthma Australia or the Starlight Foundation. A range of these organisations (and also some state and territory Health Departments) conduct formal training in consumer representation. In this context, a consumer representative may be a young
person who has extensive personal experience of paediatric health and health care, and/or who has previously undergone participation in research studies. You may know some representatives of children and young people from the health or hospital committees that you attend.

It would be remiss to complete this chapter without discussing the potential ‘over-researching’ of specific paediatric groups. Children and young people – particularly those with genetic conditions, chronic childhood illnesses or disabilities, who spend a large part of their lives engaging with hospitals, clinics and other health services – become a highly accessible population for paediatric researchers. One only needs to look at the paediatric research literature to see which groups of children, young people and their families are most often targeted – for example, children with cancer, asthma, type 1 diabetes, neurological disorders and obesity or autism. The three fundamental principles of research ethics relate to protecting the dignity, privacy and wellbeing of research participants. The paediatric researcher must consider the profile of their intended patient population, whether their research is fair and just for this group, and the possibility that over-researching or research fatigue may impact upon their sample recruitment, retention and possibly the quality of data – potentially affecting the quality and outcomes of their research. The research design must also offer an explicit and easy way for children and young people to say ‘no’ if they do not wish to participate, or they wish to withdraw from the study.

**Partnering in evidence implementation**

There are many models and frameworks for implementing research findings into practice. You may, for example, have heard about the PARIHS Model (Rycroft-Malone et al., 2013) or the Knowledge to Action
(KTA) framework (Graham et al., 2006). Regardless, evidence-implementation models always propose the initial development of an implementation plan. In the clinical research context, children and young people involved in the research design and conduct phases are in the best position to contribute excellent ideas for implementation. But any child or young person who is interested can be involved in the implementation of research that will inform the future care of themselves and others in at least two practical ways:

- Members of the implementation team ask children and young people to identify potential barriers to implementing research evidence into practice change.

- Children and young people who will be affected by the change in treatment or health care are engaged as champions to promote the acceptance, implementation and maintenance of the change.

**Partnering in research**

Practical ways of involving children and young people in the design, conduct and monitoring of research are less well developed. There are beginning expectations from government funding bodies such as the NHMRC to achieve and report on the engagement of consumer representatives (as defined earlier), but these expectations are variously applied and monitored. As discussed earlier, active training for consumer representation is already undertaken by a number of community-based organisations and charities representing adults, and some have extended this training to young people.

An example of an online resource for Australian researchers seeking to engage participants in health research can be found in a collaboration between the University of Western Australia (UWA) and the Telethon
Institute for Child Health Research, called Involving People in Research (IPR). IPR was formed following concerns over the use of health information in data-linkage research, and prompted the release of the first NHMRC Statement on Consumer Participation in 1998 (NHMRC, 2002). This Statement has since been circulated for update and feedback (NHMRC, 2014).

IPR now provides a range of resources to support consumer and community participation in health research, as well as funding for senior-level champions and dedicated staff positions to involve people in research. In addition to a series of online fact sheets and publications for researchers and the community, IPR also offers a plain-language, practical guide for establishing participation in health and medical research known as the Green Book (McKenzie & Hanley, 2008). The website of the Youth Affairs Council of Victoria (YACVIC) offers access to a report by Segal and Randall (2013), which suggests that training young people in research methods, and facilitating them to conduct and translate research with peers, is an effective mechanism for encouraging greater participation. This site also offers a useful toolkit from the NSW Commission for Children and Young People (NSWCCYP, 2016) called Taking PARTICipation seriously.

Various other models and methods are used by local governments, psychologists and social scientists to involve young people, their peers, families and communities in decision-making. These hold many possibilities for direct application to increasing engagement in health research. Successful examples of learning, researching and innovating with children and young people should not be excluded just because they fall outside the perceived context of health research.

Participating for success
Several barriers to implementing models and strategies for participation in health research have been identified. Imbalances of power and lack of control over the funding and design of research programs are commonly cited. Historically, academic institutions and health services are hierarchically structured and difficult enough for adults – let alone children and young people – to access and navigate (Fielden et al., 2007). Minority communities experience institutional racism, along with privilege and power challenges, in their relationships with academic organisations (Andrews et al., 2012). The Aboriginal and Torres Strait Islander experience of health research, for example, has been challenging in terms of both process and outcomes (Kendall et al., 2011). Gaining the trust of family and community stakeholders is another frequently identified roadblock to success, as is securing commitment to the extra time, money and effort required for effective communication between health and academic institutions, and consumers, to truly partner in research (Allen et al., 2010; Bailey et al., 2014; Shalowitz et al., 2009).

While there are limited examples of successful methodologies for participatory research with children and young people (Haijes & van Thiel, 2016), an obvious way to start is to ensure that research engagement is planned within the sociopolitical and economic context in which health care and treatment is to be delivered. Other key factors for the successful engagement of children, young people and their families as partners in health research include:

- early participation in prioritising and planning the research (including identification of need, values, scoping of the program and the extent of stakeholder involvement)
- support for the formation of partnerships (Allen et al., 2010) with adequate communication and training of stakeholders and
consumers (Andrews et al., 2012; Bailey et al., 2014)

- clear processes for deciding stakeholder capacity for collaboration, managing conflict and expectations, establishing norms for decision-making (Allen et al., 2010) and planning for ending the engagement when the research is complete

- agreeing the desired rewards or outcomes for all members and organisations involved.

### Reflection points 5.3

- The interests and needs of children and young people participating in research differ from those of adults. How do Australian human research ethics committees represent and respect these needs and interests?

- The National Statement on Ethical Conduct in Human Research lists six core values for research with Aboriginal and Torres Strait Islander peoples. These are ‘reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity’ (NHMRC 2007a: 6). What other cultural values do you believe are important in designing research with Aboriginal and Torres Strait Islander children and young people?

- Children and young people can be involved in the design, prioritisation and implementation of research that will inform their care by being part of the research or evidence implementation team. Think about some of the other ways in which children and young people can be involved in research and the implementation of evidence.
Applying new knowledge to practice

In this chapter, we have invited you to explore and expand your understanding of research and evidence-based practice. We have introduced four core principles of human research ethics (research integrity, autonomy and respect, beneficence and justice) and discussed research governance. We used a case study to illustrate how these core principles apply to research conducted in the paediatric setting and have asked you to reflect on how you can use this knowledge in your work as a paediatric nurse to support evidence based-practice for children and young people, and encourage their partnership in research.

While paediatric research is often delineated from direct clinical care, there are many occasions when the work of a paediatric clinician intersects with that of a researcher. Children, young people and their families have a right to assume that paediatric nursing care is informed by the best available research evidence. This means that professional nursing practice must rely on a foundation of good-quality research evidence, and assumes that a paediatric nurse knows how to interpret and use this knowledge in their work. As an evidence-based practitioner, the paediatric nurse must also be able to decide whether new knowledge from research is of sufficient quality to make a useful contribution to the paediatric knowledge base, or whether the impact of the research is such that it dictates a need for change in practice. Evidence implementation and evaluation are practice initiatives for improving the quality and safety of paediatric clinical care.

Paediatric nurses may also be engaged in leading clinical research or working as part of a research team. Their research may be conducted in a laboratory, ward or community setting, and be developed exclusively with other nurses or – as is more often the case – with other members of the
health-care team. There are virtually no limits to becoming a paediatric researcher, other than specialist training as a paediatric nurse and specialist training as a researcher. Obtaining research funding is always a challenge, but strong partnerships will help to focus the research on issues and questions that are of primary concern to children, young people and their families – your partners in research.

Summary

- Research and evidence are intimately linked in nursing and health care, but each makes a slightly different contribution. We can broadly distinguish research as a rigorous and systematic process for deriving new knowledge, and evidence as the knowledge that is produced and used. However, evidence from other sources is also used to inform health and treatment decisions. The experience of the clinician, the context of the health-care environment and information about the specific values and priorities of the child or young person receiving care ultimately shape decisions about how the evidence is used.

- The ethics of human research are based on the fundamental principles of research integrity, autonomy and respect, beneficence and justice. These principles attest that any risks from the research will be outweighed by the contribution of the research to improving health and health care, and that the dignity, privacy and wellbeing of the research participant will be protected at all times.

- Obtaining consent for participation in research is central to respect for persons. While all Australian states and territories have specific legislation concerning the age at which minors are deemed to have
capacity to consent to treatment, this may not apply to participation in research. The age of consent for participation in research is defined by individual maturity. Children may have the capacity to understand the nature of the research, and may give their consent in addition to their parent doing so. Mature children and young people capable of understanding the risks and benefits of their participation in research may give sole consent, with parental consent being waived in these circumstances.

- In the context of research ethics, a risk is anything that has the potential for harm, discomfort or inconvenience. Harm can be perceived or real, physical or psychological. Discomfort is a less serious form of risk.

- The inconvenience associated with participation in research may seem minimal to the researcher, but is especially relevant to the parents or carers of children and young people, who may need to take time away from work or family and who may incur financial or emotional costs as a result of their child’s participation in research.

- Practical ways of involving children and young people in the design, conduct and monitoring of research are still developing. Active training for consumer representation is already undertaken by a number of community-based organisations, and some charities representing adults have begun to extend this training to young people. There are a range of other models and methods used outside the health context that present possibilities for direct application for increasing engagement in health research.
Learning activity

Imagine that a parent has asked your advice about enrolling their 14-year-old daughter, Katy, in a research study about the emotional effects of asthma diagnosed in childhood. The parent is keen to give consent because they think it would be really good for Katy to talk about the challenges she has faced in managing her severe asthma, which was diagnosed at 5 years of age. However, Katy says she is sick of being involved in research because it never helps her and she does not want to talk any more about her illness. She just wants to get on with her life.

5.1 Katy is not assenting, nor will she give consent, to be part of the study. Can Katy’s parent overrule her consent in this situation? Explain your answer.

5.2 Katy eventually decides to be interviewed for the study, and both Katy and her mother give their consent. During the interview, Katy reveals that she sometimes manipulates her medication in order to provoke an asthma attack. Sometimes she does it because she doesn’t want to go school, and sometimes she does it to ‘pay her mother back’. Is the interviewer required to disclose this information to the parent?

5.3 In what situations could Katy be considered to have capacity to give sole consent for her participation in this research?

Further reading

This resource from the Children’s Bioethics Centre at the Murdoch Children’s Research Institute answers frequently asked questions about designing research with children and explores some difficult issues with specific reference to the Australian National Statement. The resource also covers specific types of research, such as genetic and internet-based research:


The Ethical Research Involving Children (ERIC) project (http://childethics.com) is a joint international project between UNICEF’s Office of Research, Innocenti, the Childwatch International Research Network, the Centre for Children and Young People at Southern Cross University, Australia and the Children’s Issues Centre at the University of Otago, New Zealand. The project maintains an online repository of resources to assist researchers to plan, conduct and monitor the ethics of research involving children and young people across the world.

Websites

Codes and standards for research ethics and governance referred to during this chapter include the following:

- Nuremberg Code of 1947:
There are also specific guidelines and resources for conducting ethical research with Aboriginal and Torres Strait Islander Peoples:

- **Declaration of Helsinki:**
  

- **Belmont Report:**
  

- **Australian Joint National Statement on Ethical Conduct in Human Research:**
  

- **Australian Code for the Responsible Conduct of Research:**
  

  There are also specific guidelines and resources for conducting ethical research with Aboriginal and Torres Strait Islander Peoples:

- **From the NHMRC:** *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*,
  

- **From the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS):** *Guidelines for Ethical Research in Indigenous Studies*,
  

Resources for engaging children and young people in health research include:

- **Involving People in Research and access to the Green Book:**
  

- **NSW Commission for Children and Young People,** *Taking PARTICipation seriously*, viewed 20 September 2016,
  
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**Evidence** – Contextualised knowledge from research (external) and other (internal) sources

**Research** – A systematic and rigorous process for the creation of new knowledge

**Methodology** – The research approach, activities, sample, methods, measures and analyses required to logically follow the steps of the research process to answer the research question – for example, phenomenology
**Method** – The application of a common process, tool or technique to collect research data – for example, an in-depth interview with a young person recently diagnosed with epilepsy

**Answerable research question** – A clearly articulated and focused research or practice question that is framed to maximise the efficiency and effectiveness of searching literature and choosing an appropriate research design to answer the question

**Research design** – The detailed outline or plan of how the research will proceed – for example, a proposal to explore the lived experience of young people diagnosed with epilepsy (a qualitative study). The design includes plans for funding and timelines.

**Evidence-based practice** – The application of the best available contextualised evidence within the practice setting

**Research translation** – The pathway or period during which findings from either basic or applied research are disseminated, implemented as evidence and have a measurable impact on patients, policy or practice

**Autonomy** – Respect for human beings to make their own decisions – a fundamental principle of human research ethics. This principle refers to respect for the privacy, confidentiality, customs, perceptions and cultural sensitivities of research participants, and recognises the value and intrinsic right of individuals and collectives to make decisions about participation in research.

**Research governance** – The processes by which institutions establish, conduct and oversee the ethics, quality and safety of human research. This includes establishing and operating institutional HRECs and monitoring individual researcher accountabilities for the ethical design, conduct, scientific rigour and safety of their studies. Australian institutions must also ensure that any research for which they are
responsible complies with the Australian Code for the Responsible Conduct of Research (NHMRC, 2007a) and the National Statement on Ethical Conduct in Human Research (NHMRC, 2007b).

**Standing parental consent** – Enables parents to give consent to their child’s involvement in one or more research projects about which they have been informed on the understanding that they may withdraw consent for their child’s participation for any individual project or withdraw standing consent at any time.

**Beneficence** – The act of benefiting others, or contributing to the greater good. In research ethics, beneficence relates to actions taken to remove or reduce any risk or harms associated with the research.

**Harm** – In research, harm can be perceived or real. Harm may be physical (such as pain or injury) or psychological (such as feeling guilty, upset or humiliated). Social harm relates to damage of relationships within social networks. Economic or legal harm relates to the imposition of costs or exposure to legal prosecution as a result of participation in research.

**Champion** – A person (inclusive of health professionals) who will lead and maintain support for a cause or a course of action. An evidence-based practice champion must be fully committed and adequately resourced with the appropriate knowledge and time to undertake this role.
Recognising and responding to the sick child

Elizabeth Forster and Loretta Scaini-Clarke

**Learning objectives**

In this chapter you will:

- Gain an understanding of normal assessment findings in the paediatric patient and those indicating deterioration
- Learn how to recognise a sick or deteriorating child using an appropriate framework
- Develop an understanding of how to respond to a sick or deteriorating child and provide appropriate respiratory and circulatory support
- Learn the elements of paediatric cardiopulmonary resuscitation
- Consider the importance of supporting families and parental presence during paediatric resuscitation
Introduction

As a nurse caring for paediatric patients, it is important for you to develop the ability to recognise and respond to a sick infant or child. The ability to do this is so important that a variety of projects have been undertaken, both internationally and throughout Australia, to ensure that nurses working with paediatric patients are able to recognise, respond promptly to and appropriately manage sick and deteriorating infants and children. Examples are the Between the Flags program in New South Wales, the Victorian Children’s Tool for Observation and Response (VICTOR) and the Children’s Early Warning Assessment Tool (CEWT) in Queensland. These programs aim to support the assessment skills of the clinician working with infants and children. Paediatric early warning tools help clinicians to recognise a deteriorating infant or child, and trigger an escalation in care to prevent further deterioration and achieve favourable outcomes. This chapter will provide you with a basic understanding and knowledge so that you will be able to recognise and respond to a sick and deteriorating child.

Clinical signs – a warning of deterioration – are often present in the paediatric patient as for as long as six to 12 hours before a catastrophic event. Failure to identify and treat these early warning signs can result in continued clinical deterioration until cardiopulmonary arrest. The poor outcomes associated with paediatric cardiopulmonary arrest emphasise the importance of being able to detect and respond to early signs of deterioration (McLellan & Connor, 2013).

The primary cause of paediatric cardiopulmonary arrest is respiratory in origin, and the second most common cause is circulatory failure. In both situations, the child will display signs of respiratory or cardiovascular compromise prior to deteriorating into cardiac arrest. Timely intervention
can treat or stabilise the child, preventing the progress of the condition. Sudden cardiac arrest is extremely rare in paediatrics, and is limited to a small number of uncommon conditions, such as underlying congenital cardiac disease or arrhythmias such as long QT syndrome (Gajewski & Saul, 2010).

Understanding the causes of deterioration in the paediatric patient is important for enhancing early recognition of problems. Due to their stage of development, paediatric patients have anatomical, physiological and behavioural differences that underpin their predisposition to develop illness and their ability to respond to the stress of disease. Table 6.1 reviews some of the significant respiratory and cardiovascular differences.

**Table 6.1** Respiratory and cardiovascular differences in paediatric patients

<table>
<thead>
<tr>
<th>Paediatric respiratory characteristics that increase risk of respiratory compromise</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infants are obligatory nose breathers</strong></td>
</tr>
<tr>
<td><strong>Narrow airways</strong></td>
</tr>
<tr>
<td><strong>Soft, collapsible airways</strong></td>
</tr>
</tbody>
</table>

- Submucosal glands in airway larger than in adults
- Lower pH of airway lining

Possible hyperactivity of mucous production.

May be linked to dysfunction of epithelial cells of respiratory tract, impaired mucociliary clearance and viscosity of secretions.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large tongue and adenoids</td>
<td>Lead to an increased risk of airway obstruction. Adenoids are often problematic around 2 years of age.</td>
</tr>
<tr>
<td>Horizontal, cartilaginous ribs</td>
<td>The chest wall collapses inwards when the infant increases their work of breathing. This is seen as intercostal, sternal and subcostal recession, and often results in decreased air entry.</td>
</tr>
<tr>
<td>Immature intercostal and accessory muscles</td>
<td>Primarily use the diaphragm to breathe. The lack of type II muscle fibres results in early fatigue of the infant’s respiratory muscles. Increased work of breathing results in head bob, seesaw movement between the chest and abdomen.</td>
</tr>
</tbody>
</table>
Less alveolar surface area available for gas exchange

By approximately 8–12 years of age, a child has nine times the alveoli than were present at birth.

Large head and an inability to reposition

Infants have a large occiput that can push the head forward and obstruct the airway. They lack the muscle strength or developmental ability to reposition themselves to aid breathing.

Higher metabolic rate

Greater need for oxygen to support metabolic processes and consequently higher respiratory rates.

Developmental stage of placing objects into the mouth or nose

Upper airway obstruction due to foreign objects is common, and can be life-threatening in toddlers and young children.

**Paediatric cardiovascular characteristics that increase risk of cardiovascular compromise**

Immature myocardium

Limited ability to increase contractility, making stroke volume relatively fixed. Cardiac output is increased by increasing the heart rate.
<table>
<thead>
<tr>
<th><strong>70–80 mL/kg blood volume</strong></th>
<th>Low total blood volume – 240 mL for a newborn. Small losses can result in shock.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ability to maintain blood pressure</strong></td>
<td>Hypotension is a very late sign of cardiovascular compromise. Other signs of compromise are increased HR, capillary refill, perfusion. Urine output must be observed, as it will decrease with a fall in renal perfusion.</td>
</tr>
<tr>
<td><strong>Changes from foetal circulation may continue for several weeks</strong></td>
<td>Undiagnosed congenital cardiac structural defects may present within the first weeks of life.</td>
</tr>
<tr>
<td><strong>Increased risk for fluid depletion</strong></td>
<td>Large surface area increases the risk of insensible losses. Reduced ability to concentrate urine during infancy. Larger percentage of total body fluids.</td>
</tr>
<tr>
<td><strong>Limited metabolic and physiological reserve</strong></td>
<td>If left unsupported, infants and children may become exhausted from their disease states. This may manifest as a reduction in respiratory rate or slowing of the heart rate. These are indicators that the child is rapidly approaching</td>
</tr>
</tbody>
</table>
Structured assessment of the paediatric patient

The use of a structured assessment framework can assist with your ability to perform a patient assessment (Munroe et al., 2013). Assessment frameworks can assist clinicians to prioritise assessment of critical body systems and ensure that these are methodically assessed. We will discuss two commonly used assessment approaches here: the Paediatric Assessment Triangle and the Primary Assessment Framework.

The Paediatric Assessment Triangle

Figure 6.1 represents the Paediatric Assessment Triangle (Dieckmann, Brownstein & Gausche-Hill, 2010), a rapid-assessment framework used to perform an initial assessment and to quickly identify a sick and deteriorating child.
The Paediatric Assessment Triangle works via rapid assessment of three components: the child’s appearance, work of breathing and circulation to the skin (Dieckmann, Brownstein & Gausche-Hill, 2010).

The child’s appearance relates to:

- **tone** (includes whether the child moves spontaneously, resists being examined, sits or stands (age appropriate))
- **interactiveness** (includes whether the child appears alert and engaged with clinicians/caregivers, interacts with people and environment, reaches for toys, objects)
- **consolability** (includes whether the child stops crying with holding/comforting by caregiver or has differential response to caregiver versus examiner)
- **look/gaze** (includes whether child makes eye contact with clinician, tracks visually)
- **speech/cry** (includes whether the child has a strong cry/uses age-appropriate speech).

The child’s work of breathing relates to:

- abnormal airway sounds (including snoring, muffled or hoarse speech, stridor, grunting, wheezing)
- abnormal positioning (sniffing position, tripoding or preference for seated posture)
- retractions (supraventricular, intercostal or substernal retractions, head bobbing in infants)
- flaring of the nares on inspiration.

The child’s circulation relates to characteristic abnormal features such as:

- pallor (white or pale skin or mucous membranes)
- mottling (patchy skin discoloration due to varying degrees of vasoconstriction)
- cyanosis (bluish discoloration of skin and mucous membranes).

The Paediatric Assessment Triangle provides clinicians with a rapid ‘hands-off’ 30-second (approximately) assessment that can be completed prior to the hands-on primary survey. It means that life-saving treatments can be initiated immediately if necessary.

**The Primary Assessment Framework**
We will now discuss the ABCD, primary survey, or Primary Assessment Framework for assessing the paediatric patient. The Primary Assessment Framework approach to assessment uses an ABCD assessment framework for paediatric patients. Many of the early warning tools use a variation of the primary survey in guiding the initial assessment of the paediatric patient.

The Primary Assessment Framework is designed to assist in assessing and managing clinical deterioration in order of priority. When completing a primary assessment, if life-threatening conditions are identified they must be managed prior to continuing with the assessment. The following is a brief description of the primary assessment framework:

**A** *Airway*: assessed for patency and security

**B** *Breathing*: work and rate of breathing and the effectiveness of breathing to achieve adequate oxygenation

**C** *Circulation*: heart rate, skin perfusion and evidence that the body is achieving sufficient adequate blood flow

**D** *Disability*: mental status and level of consciousness.

You will be able to use your beginning understanding of the primary assessment framework when you consider Case Study 6.1, which concerns Maggie, an infant with respiratory distress.

<table>
<thead>
<tr>
<th>Case study 6.1</th>
</tr>
</thead>
</table>

**Infant with respiratory distress**

Maggie, a 6-month-old infant, has a three-day history of a respiratory tract infection. She has been admitted to the paediatric ward diagnosed with bronchiolitis (suspected to be Respiratory
Syncitial Virus [RSV]). Upon assessment, Maggie is pale and lethargic. She has a moist cough and thick, creamy rhinorrhoea. Her respiratory rate is 48 breaths per minute and she has moderate intercostal and subcostal recession and tracheal tug. Bilateral wheeze can be heard upon auscultation. Her oxygen saturations (Sp02) in room air are 92 per cent. Her heart rate is 154 beats per minute and her temperature is 37.9ºC.

Maggie’s mother reports that she has been ‘not feeding well’ over the past few days. She last changed a wet nappy at 5.00 am (six hours ago).

**Applying the Primary Assessment Framework**

By utilising the Primary Assessment Framework when performing Maggie’s assessment, as Maggie’s nurse you are able to collect the data in systematic manner.

> **Airway:**
> - maintaining own airway; no upper airway noises
> - thick nasal secretions potential for obstructing nasal breathing.

> **Breathing:**
> - respirations are 48 breaths per minute
> - increased work of breathing evidenced by intercostal and subcostal recession
> - wheeze
> - reduced oxygen saturations in room air: 92 per cent (impaired gas exchange).
> Circulation:
   - heart rate of 154 beats per minute
   - pallor, peripheries cool
   - peripheral pulses present
   - blood pressure 100/52
   - reduced urine output
   - reduced oral intake.

> Disability:
   - lethargic
   - responses to voice on AVPU score
   - uninterested in feeding.

Recognition of clinical deterioration using a Primary Assessment Framework

You already have a beginning understanding of the elements of the Primary Assessment Framework, and you have applied this to collect assessment data about Maggie in Case Study 6.1. In this section, we will utilise the Primary Assessment Framework to provide you with a systematic and detailed review of a paediatric assessment. In most instances, a rapid assessment should be undertaken to identify the need for emergency care prior to performing a more comprehensive assessment. If, however, immediately life-threatening conditions present during the primary assessment, they must be managed immediately.
**A – Airway**

In the primary survey, A represents airway assessment. For the paediatric patient, you need to consider whether the patient can maintain their own airway. Is the airway clear or is it obstructed? An inability to maintain a patent airway is immediately life threatening and needs to take priority in the management of the patient. The child’s ability to vocalise or speak provides a rapid assessment of airway patency.

There are a number of anatomical and behavioural developmental factors that increase the paediatric patient’s risk for compromised airway. Some of these factors include having a large tongue, a soft floor of the mouth that is easily compressible, a large head and a small-sized mid-face (Cullen, 2012a). In a child with decreased or a loss of consciousness, the large tongue could easily obstruct the airway. When artificial support is given, care should be taken to hold any mask along the jawline so as not to compress the soft floor of a child’s mouth, further contributing to airway compromise. The large head with a predominant occiput can result in the child’s neck becoming flexed and obstructing the airway.

The child’s upper airway is narrow and cone-shaped, with the cricoid cartilage being the narrowest point. This anatomy places the child at increased risk of upper airway obstruction due to swelling associated with infections such as ‘croup’ (laryngotracheobronchitis).

Another important cause of airway obstruction in young children is a foreign body. Inhalation of small objects, including toys, batteries or pieces of food, can partially or completely obstruct the upper airway.

Characteristics of partial upper airway obstruction may include:

- difficulty breathing with increased work of breathing
- upper respiratory tract noises such a stridor or snoring sounds
- drooling or inability to swallow secretions
• the child positioning their neck or head to open their airway
• a history of illness or choking on a foreign object
• decreased air entry and impaired oxygenation in severe cases.

Rapidly assessing the child for the cause and degree of respiratory compromise is essential to ensure appropriate management and referral. For example, a child with a partially obstructed airway following anaesthesia may require the application of a simple airway open manoeuvre such as jaw thrust until they are more awake. However, a child with a severe episode of croup may require urgent medical attention.

Children with complete upper airway obstruction will quickly deteriorate into cardiac arrest and require an urgent emergency airway. The management of any child with acute upper airway obstruction is therefore critical. It is important that a doctor who is able to perform a difficult paediatric intubation is notified.

Children at risk of airway obstruction should be observed continuously and never left unattended.

**B – Breathing**

In the primary survey, B represents breathing – that is, assessment of the adequacy of breathing, and therefore oxygenation. In the paediatric patient, this incorporates a variety of assessment parameters, including:

• respiratory rate, which will vary depending upon the age of the infant or child, and the presence of fever or coexisting health conditions (see Table 6.2 for usual paediatric respiratory rates)
• symmetry of chest wall movement
- work of breathing, including the presence of signs such as nasal flaring and head bobbing in infants, recession or retractions, and diaphragmatic movement in conjunction with chest wall movement.

**Table 6.2** Respiratory rate parameters for paediatric age groups

<table>
<thead>
<tr>
<th>Age</th>
<th>Respiratory rate per minute</th>
<th>Consider as rapid</th>
<th>Consider factors that may affect respiratory rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn (0–28 days)</td>
<td>30–50</td>
<td>&gt;60</td>
<td>Fever</td>
</tr>
<tr>
<td>Infant (1–12 months)</td>
<td>20–30</td>
<td>&gt;50</td>
<td>Comorbidities (e.g. congenital respiratory or heart disease)</td>
</tr>
<tr>
<td>Toddler (1–3 years)</td>
<td>20–30</td>
<td>&gt;40</td>
<td></td>
</tr>
<tr>
<td>Child (4–11 years)</td>
<td>15–20</td>
<td>&gt;30</td>
<td></td>
</tr>
<tr>
<td>Adolescent (12 years and over)</td>
<td>16–18</td>
<td>&gt;24</td>
<td>Seizure activity</td>
</tr>
</tbody>
</table>
Chest recession or retractions
The assessment of chest recession or retractions is important, as normally there is minimal chest wall movement in the child because they rely upon diaphragmatic abdominal breathing. Any respiratory issue that causes increased airway resistance therefore results in the generation of increased negative intrathoracic pressure needed to produce inward airflow during inspiration causes recession (Aylott, 2006).

Breath sounds and air entry
Breath sounds and air entry, or the absence of breath sounds, can be an important element of breathing assessment in the paediatric patient. Breath sounds can alert the clinician to the nature of the respiratory issue – for example, wheezing indicates fluid in the airways and alveoli, and stridor indicates narrowing, oedema or obstruction of the trachea and upper airway.

Grunting may be heard in infants with severe respiratory distress, and indicates an effort to increase end expiratory pressure during respiration to promote gas exchange (Aylott, 2006).

Oxygen saturation
Oxygen saturations are a measure of the oxygen saturation of haemoglobin, and provide valuable information about the child’s oxygenation status. Pulse oximeters are commonly used to measure the
oxygen saturation in peripheral blood (Sp02). Normal Sp02 should be greater than 97 per cent in room air (O’Meara & Watton, 2012).

A variety of factors impact on the accuracy of readings in the paediatric patient, including movement, peripheral perfusion and skin pigmentation (Fouzas, Priftis & Anthracopoulos, 2011). This means it is important to look at oxygen saturation values in conjunction with the general clinical appearance of the child and other assessment data collected.

Table 6.2 shows the respiratory rate parameters for paediatric age groups and factors that may influence respiratory rate.

**C – Circulation**

In the primary survey, C represents your assessment of the adequacy of circulation in the paediatric patient, and involves assessing:

- heart rate and rhythm
- peripheral pulses and perfusion
- colour
- urine output
- blood pressure.

Assessing paediatric circulation requires an understanding of the way the sick infant or child responds to altered and inadequate circulatory or cardiovascular function. The sick infant or child with cardiovascular compromise will trigger compensatory mechanisms as the body attempts to maintain blood pressure and ensure that vital organs are perfused. A reduced pressure within the circulatory system will trigger the release of catecholamines (adrenaline and noradrenaline) and hormones (angiotensin
and antidiuretic hormone) that result in an increased heart rate, vasoconstriction of peripheral blood vessels and retention of sodium and water by the kidneys. These responses enable the sick infant or child to maintain blood pressure and circulation to the heart, lungs and brain. However, if the circulatory compromise is not corrected, these compensatory mechanisms will no longer be able to sustain sufficient perfusion of the vital organs and blood pressure will no longer be able to be maintained. This pre-terminal stage will be evident in a drop in blood pressure and decreased level of consciousness.

Table 6.3 shows the heart rate parameters for paediatric age groups and the factors to consider that may influence heart rate and rhythm.

Table 6.3 Heart rate parameters for paediatric age groups

<table>
<thead>
<tr>
<th>Age</th>
<th>Heart rate (beats per minute)</th>
<th>Consider as elevated</th>
<th>Systolic blood pressure (MMHG)</th>
<th>Diastolic blood pressure (MMHG)</th>
<th>Consider factors that may affect heart rate/rhythm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn (0–28 days)</td>
<td>70–190, Mean 125</td>
<td>At upper end of range and above</td>
<td>70</td>
<td>30</td>
<td>Hypoxia, fever</td>
</tr>
<tr>
<td>Infant (1–12 months)</td>
<td>80–160, Mean 120</td>
<td>At upper end of range and above</td>
<td>75</td>
<td>50</td>
<td>Comorbidities (e.g. congenital respiratory heart disease)</td>
</tr>
</tbody>
</table>
Heart rate and rhythm

During childhood, the heart rate is faster and the stroke volume continues to increase from birth until 5 years of age and then stabilises (Top, Tasker & Ince, 2011). Normal heart rates and blood pressure values are presented in Table 6.3. During early childhood, cardiac muscle fibres are immature and lack the ability to increase the strength of myocardial contractility. Stroke volume – the volume of blood ejected with each ventricular contraction – is therefore relatively fixed.

Source: Adapted from Top et al. (2011).
In children – particularly infants – cardiac output is increased primarily by increasing the heart rate. The child’s dependence on heart rate to manipulate cardiac output makes heart rate one of the most important observations in the paediatric cardiovascular assessment. Observation of trends in heart rate can provide signs of cardiovascular improvement or deterioration. However, while heart rate is a very sensitive sign of cardiovascular status, it is not a very specific sign. The child’s heart rate may be increased due to other factors such as temperature, pain or anxiety. Therefore, it is essential to evaluate the heart rate in the context of other clinical observations.

Bradycardia is an important sign of cardiorespiratory decompensation. This may occur in children who have become physiologically exhausted from respiratory or cardiac illness. For infants under 12 months of age, a heart rate of less than 60, accompanied by signs of impaired perfusion, will require cardiopulmonary resuscitation.

In the paediatric patient, stroke volume may be evaluated by assessing the volume and strength of pulses, and systemic vascular resistance may be evaluated via assessment of the child’s peripheral skin perfusion.

**Blood pressure**

Normal blood pressure is not a reliable sign of a child’s cardiovascular status. Severe cardiovascular compromise and inadequate tissue perfusion can be present despite normal blood pressure. However, performing a paediatric blood pressure assessment is important because hypotension is poorly tolerated and needs to be addressed quickly.

The paediatric patient’s compensatory mechanisms in the event of hypovolaemia work towards the maintenance of blood flow to the vital organs despite falling cardiac output due to decreased stroke volume.
(Hobson & Chima, 2013). The paediatric patient’s blood pressure is maintained by increasing heart rate and systemic vascular resistance through peripheral vasoconstriction until shock is severe. Thus a drop in blood pressure is considered a late and pre-terminal sign (Hobson & Chima, 2013). It is therefore important that early signs of circulatory compromise are detected. Clinicians must utilise heart rate, colour, perfusion, skin temperature, capillary refill times and level of consciousness to ensure that early intervention and circulatory support are initiated. In sick infants, assessing the blood pressure in the upper and lower limbs can provide information about undiagnosed congenital cardiac conditions such as coarctation of the aorta.

Note: The size of the blood pressure cuff is important to ensure accuracy of the measurement (see Figure 6.2). The cuff bladder should encircle 80–100 per cent of the mid-upper arm circumference (Ostchega et al., 2014). Table 6.4 provides a guide for appropriate blood pressure cuff sizes.

Figure 6.2 Blood pressure cuffs

Table 6.4 Blood pressure cuff sizes
<table>
<thead>
<tr>
<th>Age</th>
<th>Cuff width</th>
<th>Cuff length</th>
<th>Maximum arm circumference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>6 cm</td>
<td>12 cm</td>
<td>15 cm</td>
</tr>
<tr>
<td>Child</td>
<td>9 cm</td>
<td>18 cm</td>
<td>22 cm</td>
</tr>
<tr>
<td>Adolescent</td>
<td>10 cm</td>
<td>24 cm</td>
<td>26 cm</td>
</tr>
</tbody>
</table>

Source: Adapted from the National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents (2004); Ostchega et al. (2014).

Peripheral pulses and perfusion

Pulses should be checked both centrally and peripherally, and evaluated for differences. Marked variation in intensity of pulses may be indicative of blood being directed towards central organs and away from the peripheries. This is a compensatory mechanism that can occur in conditions such as hypovolaemia.

The strength and volume of the pulse provide information about stroke volume. A weak or thready pulse – especially if found centrally – is a worrying sign of poor cardiac output. This may be present in a child with severe vasoconstriction and/or impaired cardiac function.

The carotid pulse can be used to assess a central pulse in children. Because infants often have short, chubby necks, the most reliable locations to palpate central pulses in infants are the brachial and femoral arteries. Absent or weak femoral pulses may be indicative of undiagnosed congenital cardiac conditions where upper limb pulses are adequate.
The colour and temperature of skin can reflect the adequacy of peripheral perfusion and provide information about systemic vascular resistance. Skin mottling has been demonstrated to be a reliable measure of skin hypoperfusion and is responsive to changes in peripheral vasoconstriction (Ait-Oufella et al., 2013).

Peripheral vasoconstriction is part of the compensatory response designed to maintain blood pressure during cardiovascular compromise, and is therefore an indirect measure of cardiovascular function. Severe alterations in peripheral perfusion, such as mottling, pale, cold skin and decreased peripheral pulses, are indicative of serious cardiovascular dysfunction.

When assessing skin temperature and perfusion, it is valuable to identify the level of skin involvement so that reassessment for change is possible. For example, the skin may be cool and mottled to the level of the child’s knee.

Factors such as low environmental temperatures and fever can also cause peripheral vasoconstriction, resulting in pale or cool skin. Therefore, it is important to apply your assessment finding to the clinical context.

**Capillary refill**

Capillary refill is often used to assess skin perfusion in the paediatric patient. It refers to the amount of time for the capillary bed to return its colour after pressure has been applied to cause the area to blanch (Pickard, Karlen & Ansermino, 2011). A variety of factors may affect capillary refill time, including:

- *age* (with neonates having an upper limit of three seconds and children having an upper limit of two seconds)
• *environmental, skin and core temperature* – capillary refill time tends to increase with cooler ambient temperature and decrease with warmer environments, such as when radiant heaters are used; skin temperature also affects capillary refill time, and reductions in skin temperature tend to be reflected in an increased capillary refill time; core temperature also influences capillary refill time with each 1°C rise in core temperature, resulting in a shorter capillary refill time (Pickard et al., 2011).

• *duration of application and location of pressure* applied.

There is no consensus about the correct duration of pressure application prior to measuring capillary refill time, and the variables range from three to seven seconds – or sufficient time to cause blanching. Recent paediatric studies recommend using your index finger to apply enough pressure to cause the skin to turn pale and applying pressure for five seconds (Crook & Taylor, 2013).

A variety of sites have been used for testing capillary refill, including the forehead, sternum, nail bed of fingers or toes, or pulp or pads of fingertips and heels. The location used may affect the capillary refill time – for example, the capillary refill time at the heel may show a longer time than at the finger, and fingertip capillary refill time is faster than the sternum capillary refill time (Crook & Taylor, 2013).

Urine output

A normal urine output for a child is approximately 1 mL/kg/hour. The normal urine output for an infant is >2 mL/kg/day, which equates to approximately six to eight wet nappies per day. An infant with no wet nappy for more than four to six hours may have a decreased urine output. Weighed nappies can be used to calculate urine output more accurately. If
infants have diarrhoea and evidence of dehydration, an indwelling catheter may be needed to accurately assess urine output.

The colour and concentration of the urine also provide information about the child’s hydration status. A reduction in urine output with concentrated urine is often associated with hypovolaemia. As part of the compensatory mechanism, increased concentrations of antidiuretic hormone, angiotensin and aldosterone act on the kidneys to promote reabsorption of water and sodium into the body and reduce the volume of urine produced. Renal blood flow may also be decreased, resulting in further decreases in urine output.

![Weighed disposable nappy](image)

**Figure 6.3** Weighed disposable nappy

It is important to remember that some paediatric conditions that may cause hypovolaemia may have increased urine output – for example, diabetic ketoacidosis, diabetes insipidus and adrenal insufficiency (Hobson & Chima, 2013). In these conditions, urine output may continue to be high despite the child’s depleted intravascular volume. Performing a urinalysis
and specific gravity can provide more information. During the neonatal period, infants have a reduced capacity to concentrate urine, and may be at greater risk of dehydration.

### Case study 6.2

**A child with circulatory compromise**

Robert is a 7-year-old boy who fell from his bicycle yesterday. He sustained a contusion and laceration to his liver. Robert was admitted to the paediatric ward for observation. When you assess Robert, you notice that he looks pale, his heart rate has increased to 140 beats per minute and his peripheral pulse is difficult to feel and thready. You assess his peripheries to be cool up to his elbows. His capillary refill time is three seconds and his respiratory rate is 22 breaths per minute. When you take his blood pressure, it has fallen minimally from 105/55 to 100/54 mmHg.

Robert is displaying clinical signs of circulatory compromise due to blood loss from his liver injury. His tachycardia and vasoconstriction demonstrate physiological attempts to compensate for the blood loss; however, if Robert does not receive urgent medical treatment he will quickly decompensate into cardiovascular collapse.

**D – Disability**

The assessment of disability relates to the assessment of the patient’s neurological status. It requires a focus on the general appearance, consciousness level and responsiveness of the child. Alteration in
neurological status may be in response to a primary neurological condition or as a secondary response to other disease processes.

A sick or deteriorating child will often be listless or uninterested in their surroundings, have inappropriate responses to the parents or caregivers, or have a decreased level of consciousness. Reduced level of consciousness in children with respiratory or cardiovascular compromise is a marker of poor cerebral perfusion, and signals the need for urgent cardiorespiratory support.

Muscle and limb tone may provide information about the child’s neurological status. Hypotonia may be present in the exhausted or seriously ill child. Abnormal posturing, such as decorticate (upper limb flexion, lower limb extension) or decerbrate (upper and lower limb extension posturing), is indicative of raised intracranial pressure and serious brain dysfunction (O’Meara & Watton, 2012). Hypertonia or tonic–clonic movements are associated with seizures in children after infancy. Infant seizures are often subtle and easily missed, possibly presenting as apnoeas or subtle movements such as tongue thrusting, lip smacking or bicycling leg movements (Kim, Brousseau & Konduri, 2009).

During illness, increased metabolism and disruption to feeding can often cause hypoglycaemia, which can result in alterations in neurological status, including jitteriness, hypotonia, lethargy and seizures (DePuy et al., 2009; Hoops et al., 2010). It is important that a blood glucose level is included in the assessment of sick infants and young children (O’Meara & Watton, 2012).

Up to 12 months of age, an infant will have an open anterior fontanel. A tense or bulging fontanel is indicative of raised intracranial pressure: a normal fontanel should be rounded, soft and pulsatile. Performing a paediatric neurological assessment is challenging because of the different cognitive abilities at each developmental stage. In addition, there can be
significant variations in ability within each developmental stage, making it difficult for clinicians to determine what the child’s normal behaviour would be. Psychological factors such as fear of strangers and anxiety often alter a child’s behaviour, adding a further challenge to the neurological assessment.

Parents and caregivers are often able to provide valuable information regarding alterations from their child’s usual behaviour. When they present with their sick child, caregivers will often report that the child is not their usual self or has been behaving abnormally. Engaging the child’s caregivers to assist in neurological assessment is especially important to assist with achieving an accurate assessment.

Changes in pupil size and reactivity can provide important information about the neurological status. In an unconscious child, large and non-reactive pupils are an important sign of life-threatening intracranial hypertension. Small, pinpoint pupils may indicate ingestion or use of narcotic medications (O’Meara & Watton, 2012).

**Paediatric neurological assessment tools**

Two commonly used paediatric neurological assessment tools, the AVPU and Paediatric Glasgow Coma Scale (GCS), will be discussed in this section to help you gain an understanding of this important aspect of assessing the paediatric patient.

A quick tool that may be used to assess the paediatric patient’s level of consciousness is the AVPU (Cullen, 2012a):

- **A** Alert
- **V** responds to **V**oice
**P** responds to **P**ain

**U** Unresponsive

This tool is very useful, as it enables the clinician to quickly assess whether the neurological status is normal, slightly abnormal or seriously abnormal. If a child is only responding to painful stimuli, this indicates that the neurological status is seriously abnormal and that the child may no longer be able to protect their own airway.

Medical staff able to intubate the child should be involved in assessing and managing the child. Any child with an altered level of consciousness or mental status needs close and regular monitoring because they are at risk of further deterioration.

The GCS (see Table 6.5) is also used for the assessment of neurological status. It provides a more comprehensive assessment than the AVPU. The GCS has been modified for infants and children to accommodate for the developmental differences. A GCS of 8 is a serious low score and is associated with the need for clinical interventions to provide airway protection. A GCS of 8 is approximately equivalent to a ‘P’ on the AVPU scale.

**Table 6.5** Glasgow Coma Scale

<table>
<thead>
<tr>
<th>Paediatric GCS</th>
<th>Infant &lt; 1 year</th>
<th>Child 1–5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye opening 4</td>
<td>Spontaneous</td>
<td>Spontaneous</td>
</tr>
<tr>
<td>3</td>
<td>Shouts</td>
<td>Voice</td>
</tr>
<tr>
<td>Score</td>
<td>Pain Response</td>
<td>Motor Response</td>
</tr>
<tr>
<td>-------</td>
<td>---------------</td>
<td>----------------</td>
</tr>
<tr>
<td>2</td>
<td>Pain</td>
<td>Pain</td>
</tr>
<tr>
<td>1</td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spontaneous movements</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>Withdraws to touch</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>Withdraws to pain</td>
</tr>
<tr>
<td>3</td>
<td>Abnormal flexion</td>
<td>Abnormal flexion</td>
</tr>
<tr>
<td>2</td>
<td>Abnormal extension</td>
<td>Abnormal extension</td>
</tr>
<tr>
<td>1</td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spontaneous movements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Withdraws to touch</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Withdraws to pain</td>
</tr>
<tr>
<td></td>
<td>Abnormal flexion</td>
<td>Abnormal flexion</td>
</tr>
<tr>
<td></td>
<td>Abnormal extension</td>
<td>Abnormal extension</td>
</tr>
<tr>
<td></td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spontaneous movements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Withdraws to touch</td>
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<tr>
<td></td>
<td></td>
<td>Withdraws to pain</td>
</tr>
<tr>
<td></td>
<td>Abnormal flexion</td>
<td>Abnormal flexion</td>
</tr>
<tr>
<td></td>
<td>Abnormal extension</td>
<td>Abnormal extension</td>
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<tr>
<td></td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spontaneous movements</td>
</tr>
<tr>
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<td>Withdraws to touch</td>
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<tr>
<td></td>
<td></td>
<td>Withdraws to pain</td>
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<tr>
<td></td>
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<td>Abnormal flexion</td>
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<td></td>
<td>Abnormal extension</td>
<td>Abnormal extension</td>
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<tr>
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<td>No response</td>
<td>No response</td>
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<td>Spontaneous movements</td>
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<tr>
<td></td>
<td>Abnormal flexion</td>
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<tr>
<td></td>
<td>Abnormal flexion</td>
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<tr>
<td></td>
<td>Abnormal extension</td>
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</tr>
<tr>
<td></td>
<td>No response</td>
<td>No response</td>
</tr>
</tbody>
</table>

Verbal response 5: Coos, smiles

Appropriate words, phrases
<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Cries and inconsolable</td>
<td>Inappropriate words</td>
</tr>
<tr>
<td>3</td>
<td>Persistent inappropriate crying or screaming</td>
<td>Persistent crying or screaming</td>
</tr>
<tr>
<td>2</td>
<td>Grunts, agitated or restless</td>
<td>Grunts or groans</td>
</tr>
<tr>
<td>1</td>
<td>No response</td>
<td>No response</td>
</tr>
</tbody>
</table>

**Reflection points 6.1**

- Early warning tools have been developed to assist clinicians to recognise signs of deterioration in a paediatric patient and trigger an escalation in care, such as an urgent medical review. Consider your clinical experiences in the acute paediatric setting and the early warning tools you have seen or used. What did you find most helpful in relation to the tools? What further learning did they stimulate for you in relation to the care of acutely ill children?

- We have now reviewed two structured paediatric assessment tools: the Paediatric Assessment Triangle and the Primary Assessment Framework for the paediatric patient. What are
some of the differences between these approaches? For example, does one approach precede the other?

- The Primary Assessment Framework assesses airway, breathing, circulation and disability. Airway assessment includes history and ability to maintain a clear airway – considering anatomical, physiological and developmental characteristics that increase the paediatric patient’s risk for airway compromise, as well as signs of airway compromise, such as inability to speak, manage oral secretions, work of breathing, abnormal breath sounds, posturing in an attempt to open airway and decreased air entry upon auscultation and impaired oxygenation. Why is urgent management of a compromised airway critical in the paediatric patient?

- Breathing assessment incorporates respiratory rate, symmetry of chest wall movement, colour, air entry and breath sounds, and signs that indicate increased work of breathing, including recession or nasal flaring, or head bobbing and marked diaphragmatic movement in the infant. Oxygen-saturation measurements will also complement this data. Why should paediatric nurses look at oxygen-saturation readings in conjunction with their complete respiratory assessment?

- The assessment of circulation involves evaluating heart rate and rhythm, peripheral pulses and perfusion, colour and urine output. It is essential to understand the child’s normal response and compensatory mechanisms that operate in response to compromised circulatory or cardiovascular function. How might these mechanisms affect heart rate and blood pressure? Why is it
important to assess peripheral pulses, perfusion, capillary refill and urine output?

- Disability assessment equates to neurological assessment, and we have reviewed two tools that can assist in this assessment the AVPU and the paediatric GCS. If you detected a deterioration in a child’s conscious level or responsiveness, what immediate actions would you take?

## Case study 6.3

**An adolescent with neurological compromise**

Angela is a 14-year-old girl who presents to the emergency department accompanied by her mother. She had been generally unwell for the previous day and her parents had taken her to the family general practitioner, who had prescribed amoxicillin. Yesterday evening, Angela complained of severe headache and when Angela’s parents turned her light on in her room this morning, Angela screamed at them to turn it off. Her mother reports she was ‘really aggressive and confused as to where she was and not her usual self’.

Angela is brought into the emergency room to be assessed. Responding to the AVPU method, Angela intermittently opens her eyes when you call her name, consistently withdraws from painful stimuli and continually moans, ‘My head is killing me’’, appears agitated and moves about the bed continuously. She does not want to cooperate with your examination and her mother states, ‘This is not like her at all.’ She starts vomiting as you take her vital signs. Her heart rate is 105, respiratory rate 22, temperature 39.5°C and
blood pressure 90/51 mmHg. Angela has no visible rash; however, her capillary refill time is slowed. Her mother reports that she hasn’t passed urine this morning.

Angela displays serious signs of neurological compromise. She needs to be closely monitored, should receive urgent fluid resuscitation and must be assessed further to ensure that she is able to adequately protect her airway. Angela is stabilised and transferred to the paediatric intensive care unit. She is diagnosed with bacterial meningitis and sepsis.

**Responding to the sick child**

A timely response to the sick child generally requires a team approach. The severity of illness generally will indicate the urgency of treatment. Early warning tools incorporate the activation of timely responses to clinical assessment findings. This supports the clinician’s decision-making and reinforces the need to activate prompt clinical reviews.

Similar to assessment, a structured framework can be used to guide the management of the seriously sick child. Following an A, B, C, D approach, any serious or life-threatening problems must be addressed before continuing with the assessment. For example, if breathing is found to be inadequate, action must be taken to support the breathing before continuing on to assess the circulation.

There has been a significant amount of research into systems that improve the coordination and delivery of emergency care. Often poor communication or inadequate communication systems have been found to create barriers to the effective delivery of timely care. Nurses need to understand the communication processes for individual clinical settings
and how to effectively activate a timely clinical review or call for help in an emergency – for example, when and how to initiate a Medical Emergency Team (MET) response.

Paediatric emergency equipment should be available in all clinical areas where children are cared for. As a nurse caring for children, it is important that you are familiar with this equipment and know how to select the appropriate size. There are many resources and algorithms available to assist with paediatric emergency procedures. One example is the Australian Resuscitation Council website (http://resus.org.au).

**Respiratory support**

*Airway and breathing*

Respiratory support comprises both airway and breathing support. Some children may require assistance in one of these areas, while others will require it in both.

Secretions can block the child’s airway. Infants primarily breathe through their noses, so suctioning nares that are blocked with secretions can quickly relieve airway obstruction. Oropharyngeal suction can be useful if children are unable to remove oral secretions that pool at the back of the oropharynx. It is advisable to perform oral suction under direct vision to avoid pushing a foreign body back into the airway and causing further obstruction. Appropriate personal protective equipment (PPE) should be utilised when performing this procedure, and would include gloves, mask and goggles.

Supporting a child’s airway can be achieved by effective positioning of the head. For infants, the neutral position optimally opens the airway, while a slightly extended position described as ‘sniffing’ is used for children over 1 year of age. It is important to avoid neck extension (which
would be used in an adult) because this collapses the soft airways, resulting in airway obstruction. Young babies do not have the muscle strength to reposition their heads. Care should be taken when positioning an infant to ensure that the head is supported to avoid airway obstruction.

Children at risk of airway obstruction should be observed continuously and never left unattended. In cases where a child has a partially obstructed airway due to swelling or a foreign body, it is prudent to avoid upsetting the child to prevent exacerbating respiratory distress (Fitzgerald & Kilham, 2003). Strategies include leaving a toddler sitting on the parent/caregiver’s lap and avoiding unnecessary invasive procedures if at all possible until someone is present who can confidently manage the airway. Continuous observation and preparation of emergency airway equipment are required because the airway may deteriorate suddenly.

Adrenaline nebulisers may be prescribed and used to relieve the symptoms of upper airway swelling. The administration of adrenaline causes vasoconstriction to reduce airway swelling, which provides temporarily relief. It is important to monitor these children closely, as the airway obstruction may return as the adrenaline effect wears off. If required, adrenaline nebulisers can be repeated. The use of adrenaline can be very effective in providing time for suitably skilled staff to attend the child. The recommended dose of nebulised adrenaline is 0.5 mL/kg of the 1:1000 solution, up to maximum of 5 mL (Fitzgerald & Kilham, 2003; Shann, 2014). The dose of adrenaline can be repeated if necessary.

A lowered level of consciousness can result in airway obstruction due to the child’s tongue falling back into the oropharynx. Performing a ‘chin lift’ or ‘jaw thrust’ manoeuvre lifts the tongue from the posterior oropharynx to open the airway. In an unconscious patient, an oropharyngeal airway can also be used to maintain the airway.
A small number of children may present to hospital with a tracheostomy tube in situ. Paediatric tracheostomy tubes have a very small diameter and therefore can block easily. Ensuring patency of the tracheostomy tube is an essential element in the airway management of these children. Passing a suction catheter to suction into the tracheostomy tube can both remove secretions and assess the patency of the tube. If the tracheostomy is blocked, a tube change is required. Children presenting to hospital with a tracheostomy tube in situ should have their own supply of appropriately sized tracheotomy tubes with them. Their caregivers will have experience in changing the tracheotomy tube. Consider utilising these resources if required.

![Figure 6.4 Insertion of oral airway](image)

**Figure 6.4 Insertion of oral airway**

**Oxygenation**

Oxygen should be an early intervention for any sick or deteriorating paediatric patient. For patients with decreased oxygen saturations in room air, oxygen therapy can be applied using a paediatric Hudson mask with a minimum flow rate of 4 L/min. If required, higher percentages of oxygen can be delivered using a paediatric non-rebreathing mask with a reservoir
bag. Using an appropriately sized mask and flow rate is important to prevent the retention and rebreathing of carbon dioxide. Nasal prongs can also be used to deliver lower flows of oxygen (see Figure 6.5). Generally, in paediatric patients, the prongs are taped in place using a protective hydrocolloid dressing under the tape to protect the skin.

Figure 6.5 Nasal prongs

**Circulatory support**

Vascular access is important for paediatric patients, and will often be obtained via the insertion of a peripheral cannula upon admission and before problems occur, as the peripheral vasoconstriction that occurs in response to hypovolaemia, for example, can make the already small peripheral veins of an infant or child even more difficult to cannulate. In infants and children, vascular access may be obtained via peripheral veins, including the dorsum of the hand, wrist, forearm and the antecubital fossa, as well as the foot and ankle where the long saphenous vein may be accessed (ARC, 2016c). In infants, a scalp vein is also sometimes used.

If a child is seriously ill and deteriorating, intravenous access should be attempted for no more than 90 seconds. Failure to obtain access in this
time period requires alternative access to be attempted. If a suitably skilled person is available to insert a central venous line, this may be used. Alternatively, the intraosseous route may be used to gain emergency vascular access.

Intraosseous needles are usually used in infants and children up to approximately 6 years of age, as changes to the vascularity of the bone marrow and thickening of the bone after this age make it harder to obtain access. However, if an intraosseous drill is available, the intraosseous route may be used for older children and adults (Cullen, 2012b). The location for insertion of an intraosseous needle in infants and young children is the anterior and medial surface of the tibia, approximately 1–2 cm below the tibial tuberosity (see Figure 6.6) (Cullen, 2012b). The intraosseous route can be used for medications and fluids. Fluids cannot run via gravity, but must be injected or administered via an infusion pump.

![Intraosseous cannulation at the proximal tibia](image)

**Figure 6.6** Intraosseous cannulation site in children
Once vascular access has been obtained, fluid resuscitation and/or medications may be administered. If hypovolaemia is suspected as a cause of circulatory compromise, then the administration of an initial 20 mL/kg bolus of a crystalloid solution such as 0.9 per cent sodium chloride is recommended and the child’s response to this initial bolus is then assessed (ARC, 2016b). Further boluses of crystalloid solutions or colloids such as 4 per cent albumin may then be ordered by the physician.

Collection of relevant blood samples should be considered at the time of obtaining vascular access. These could include venous blood gas, glucose level, electrolytes, full blood count, cross match, blood cultures and coagulation profile depending on the patient’s presentation or diagnosis.

A practical method for quickly and accurately administering fluid resuscitation in children is to use 50 mL syringes to draw up and inject the fluid bolus.

After administration of a fluid bolus, it is important to reassess the child’s circulation observations to determine the effect of the fluid in improving the cardiovascular state. Providing adequate fluid resuscitation is critical; equally, however, excessive fluid resuscitation can be harmful, so it is imperative to continue to monitor the child’s response to fluid resuscitation (Myburgh & Finfer, 2013).

**Paediatric basic and advanced life support**

So far, we have discussed strategies to provide respiratory and circulatory support to the deteriorating child. We will now provide an overview of
paediatric cardiopulmonary resuscitation that may be required if the initial measures of respiratory and circulatory support are not successful in averting further deterioration. It is important to distinguish between **basic life support** and **advanced life support**. Basic life support refers to efforts made to restore or maintain airway, breathing and circulation that do not require adjunct equipment such as airways and masks. Advanced life support involves basic life support with the addition of more invasive measures such as advanced airway management, intubation, intravenous access and defibrillation.

We have already discussed some basic airway support manoeuvres and establishing intravenous access. We will now provide an overview of cardiopulmonary resuscitation and some more invasive respiratory support measures. **Table 6.6** provides a summary of the latest guidelines for paediatric cardiopulmonary resuscitation and cardiac compression delivery site and depth, and ratio of cardiac compression to ventilation.

**Table 6.6 Paediatric cardiopulmonary resuscitation**

<table>
<thead>
<tr>
<th>Child age</th>
<th>Infant &lt;1 year</th>
<th>Child 1–8 years</th>
<th>Older child &gt;8 years or adult</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pulse check</strong></td>
<td>Australian resuscitation guidelines now recommend check for no pulse or ‘signs of life’ for all age groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Head tilt position</strong></td>
<td>Neutral position</td>
<td>Slightly extended sniffing position from 1 year</td>
<td>Semi- to full-extension head tilt with chin lift</td>
</tr>
</tbody>
</table>

For older child,
<table>
<thead>
<tr>
<th>Compression site</th>
<th>Centrally on the lower half of the sternum</th>
<th>Centrally on lower half of sternum</th>
<th>Centrally on lower half of sternum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compression delivery method</td>
<td>Pressure with two thumbs or two fingers</td>
<td>Pressure with heel of one hand</td>
<td>Pressure with heel of both hands</td>
</tr>
<tr>
<td></td>
<td>In the two-thumb technique, hands encircle chest and thumbs compress the sternum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compression depth</td>
<td>4 cm or approximately one-third depth of anterior posterior dimension of the chest</td>
<td>4–5 cm or approximately one-third depth of anterior posterior dimension of the chest</td>
<td>5 cm or approximately one-third depth of anterior posterior dimension of the chest</td>
</tr>
</tbody>
</table>
Basic life support rescue by one or two rescuers

Compression: 15:2
Ventilation ratio

ECC rate/minute  Compression rate irrespective of age or ratio is approximately 100–120 compressions per minute

Time for one cycle  One compression every 0.6 seconds or almost two per second five cycles in two minutes

Advanced life support rescue by two health-care rescuers

Compression: 15:2
Ventilation ratio

ECC rate/minute  Compression rate irrespective of age or ratio is approximately 100–120 compressions per minute

Time for one cycle  Five cycles per minute

Source: Adapted from Australian Resuscitation Council (2016a).

In situations where the infant or child has stopped breathing or respiration is insufficient, the child should be supported by providing bag and mask ventilation. In most cases, this should be provided by using a
paediatric self-inflating bag attached to oxygen and with an appropriately sized face mask. A correctly sized mask covers the mouth and nose, and achieves a seal when held gently on the child’s face. To effectively hold the mask, the thumb and index finger form a ‘C’ around the mask while the other fingers are placed along the jawline.

When providing bag and mask ventilation, you should observe the rise and fall of the chest. Excessive pressure will result in air being forced into the stomach, which in turn can splint the diaphragm, inhibiting effective air entry. The insertion of a nasogastric tube can be useful to decompress the stomach.

It is worthwhile obtaining paediatric mannequins to be able to practise basic life support with a peer or colleague. Your university clinical laboratory on campus or the clinical educator in the paediatric setting will be able to assist you to engage in this important preparation for paediatric cardiopulmonary resuscitation.

**Parental presence during resuscitation**

Parents may wish to be present during resuscitation. If this is the case, it is very important to have an experienced staff member available to support the family. Some nurses may worry that witnessing resuscitation could be distressing for parents; however, an Australian study of families whose child required resuscitation in the paediatric intensive care unit found that parents who did not witness their child’s resuscitation experienced greater distress than the parents who stayed (Maxton, 2008).

Family members such as siblings will also need to be supported at an appropriate location and, depending on the circumstances, may be cared for by another family member in the patient lounge or ward play area. In
some settings, such as paediatric intensive care units, a nurse or other member of the multidisciplinary team not directly involved in the resuscitation may be available to talk with older siblings who, although not present for the resuscitation, may want to discuss their concerns.

As a nurse caring for paediatric patients, your ability to provide safe care is paramount. Recognising the sick infant or child and responding promptly can prevent deterioration and life-threatening respiratory and circulatory collapse. From your reading and reflection on the case studies in this chapter, you should now be well equipped with the ability to assess an infant or child using appropriate assessment frameworks and tools, be able to detect signs of deterioration and be able to respond quickly and effectively to escalate the need for an urgent medical review of the patient, and provide respiratory and circulatory support if needed to prevent further deterioration.

**Summary**

- Paediatric patients have distinct developmental, anatomical and physiological characteristics that increase their susceptibility to respiratory and circulatory compromise. Respiratory and heart rates vary according to age, and the assessment of airway, breathing, circulation and disability involves obtaining and evaluating key assessment data within each element of the primary survey in order to detect abnormalities and signs of deterioration that necessitate an escalation in care and medical review.

- Early-warning tools such as the Paediatric Early Warning Score (PEWS), the Cardiac Children’s Hospital Early Warning Score (CCHEWS) or Between the Flags may be used in paediatric
nursing practice to assist nurses to identify a child who is deteriorating and who warrants an urgent and appropriate response.

- A deteriorating child may require airway and breathing and/or circulatory support, so it is essential that paediatric nurses know how to support the child’s airway and to provide appropriate oxygenation using suitable devices (high-flow nasal prong oxygen, masks, or bag and mask ventilation). Circulatory support requires vascular access, either through intravenous or intraosseous routes. If intravenous access is not obtained and there is an urgent need for fluid resuscitation and medications, the intraosseous route is used. Initial fluid resuscitation for hypovolaemia is generally a 20 mL/kg bolus of 0.9 per cent normal saline.

- If initial measures to support respiration and circulation are unsuccessful, then cardiopulmonary resuscitation may be required. The correct head tilt position, appropriate mask, compression site, depth and ratio of compression to ventilation will depend on whether the patient is an infant, child or adolescent, and the number of rescuers. Paediatric nurses need to practise resuscitation skills regularly to ensure their competence in this area.

- Support for the family is integral to effective care for the sick and deteriorating child, and family members should have a designated support person during resuscitation to answer questions and provide information and emotional support. Parental presence during paediatric resuscitation can be achieved provided there is adequate support available, but will also be an individual family’s choice.
Learning activity

*Case Study 6.1* introduced you to Maggie, a 6-month-old infant with suspected RSV bronchiolitis. This learning activity encourages you to explore the nursing assessment and management of Maggie. Read the information below, then answer the questions that follow.

**Nasopharyngeal suctioning and bronchiolitis**

Nasopharyngeal (NP) suctioning could be very effective to assist Maggie with her breathing. The NP suctioning procedure involves the insertion of a narrow, flexible suction catheter gently into the nasal passage in a similar fashion to a nasogastric tube. The depth of insertion should be no deeper than the distance from the tip of the nose to the tragus of the ear. The suction pressure should be no greater than \(-120\) mmHg, and should only be applied as the catheter is withdrawn. The entire procedure should take less than 15 seconds. Because infants are unable to cooperate, often a second person is required to secure the infant to prevent nasal trauma during the procedure.

**High-flow nasal cannulae therapy and bronchiolitis**

High-flow nasal cannulae (HFNC) therapy provides respiratory support for infants and children by delivery of warmed and humidified air/oxygen blend at high flow rates. HFNC therapy can be effective in decreasing work of breathing. When it has been used for paediatric patients with bronchiolitis, the need for invasive respiratory support such as intubation and mechanical ventilation has been avoided. Research is continuing to emerge regarding HFNC and a large multi-centre paediatric study is currently underway in Australia and New Zealand to determine the
efficacy of HFNC compared with standard oxygen in the treatment of bronchiolitis (Franklin et al., 2015). Early research indicates that paediatric patients generally respond to HFNC within one to two hours of initiation, demonstrating a reduction in heart rate and respiratory rate towards a normal range and those infants who did not respond could be escalated to alternative respiratory support (Mayfield et al., 2014).

Our understanding of the mechanism of respiratory support in HFNC is growing, and it is thought that the high flow provides some continuous positive airway pressure (CPAP), which facilities an opening of the airways to promote gas exchange (Beggs et al., 2012; Schibler et al., 2011). This is achieved during expiration, when patients expire ‘against’ the high flow oxygen, which creates a resistance and therefore positive end expiratory pressure (Pham et al., 2015; Schibler & Franklin, 2016). The heat and humidification of HFNC enhance conductance and pulmonary compliance and reduce rebreathing of carbon dioxide by washing out of nasopharyngeal anatomical dead space during expiration (Schibler & Franklin, 2016). Furthermore, HFNC has been shown to reduce the work of breathing in infants, as indicated by a reduction in workload of the diaphragm (Pham et al., 2015). When expiration occurs against resistance provided by the high flow, this splints the airways, keeping them open; therefore, respiratory muscles such as the diaphragm do not need to work so hard, and fatigue of respiratory muscles is reduced (Morley, 2016).

6.1 Based on your reading in this chapter, what assessment data in the case study indicate that Maggie is experiencing respiratory distress?

6.2 Considering that infants are obligatory nose breathers, and that bronchiolitis results in copious nasal secretions that increase airway resistance and respiratory distress, what nursing interventions could you implement to address this issue for Maggie?
6.3 What is HFNC therapy, and why is it used in infants with bronchiolitis?

6.4 What additional concerns (other than respiratory distress) are significant for Maggie?

Further reading

Akre, M et al. 2010, Sensitivity of the Pediatric Early Warning Score to identify patient deterioration, *Pediatrics*, **125**, pp. e763–e770. This article provides an overview of the Paediatric Early Warning Score and includes an image of the tool.


Paul, SP 2013, Managing children with raised intracranial pressure: part one (introduction and meningitis), *Nursing Children and Young People*, **25**(10), pp. 31–6. This article provides an overview of brain anatomy, intracranial pressure, and meningitis assessment and management in paediatric patients.


This article can be accessed to enhance your understanding of high-flow nasal cannulae oxygen therapy for infants with bronchiolitis.
References


Beggs, S, Wong, ZH, Kaul, S, Ogden, KJ & Walters, JAE 2012, High-flow nasal cannula therapy for infants with bronchiolitis (protocol), *Cochrane Database of Systematic Reviews*, 2, art. no. CD009609.


Hoops, D et al. 2010, Should routine peripheral blood glucose testing be


National High Blood Pressure Education Program Working Group on


**Paediatric early warning tools** – Tools that assist nurses to recognise signs and symptoms indicating deterioration in paediatric patients; these include triggers and directions for escalations in management, including urgent medical review

**Paediatric Assessment Triangle** – A tool that can be used to complete a rapid ‘hands-off’ 30-second (approximately) assessment of the paediatric patient. The tool assesses the child’s appearance, work of breathing and circulation to the skin.

**Primary Assessment Framework** – An assessment framework that provides a ‘first look’ at body systems – for example, respiratory, cardiovascular and neurological. If an abnormality is detected, it should be addressed immediately.

**Basic life support** – Efforts made to restore or maintain airway, breathing and circulation that do not require adjunct equipment such as airways or masks. An example would be a first responder performing cardiopulmonary resuscitation in a public area.

**Advanced life support** – Incorporates basic life support as well as more invasive measures such as advanced airway management, intubation, intravenous access and defibrillation
Mental health and illness in childhood and adolescence

Jennifer Fraser, Lindsay Smith and Julia Taylor

Learning objectives

In this chapter you will:

• Be introduced to the concept of determinants of child and adolescent mental health

• Gain an understanding of mental disorders and mental health problems experienced in childhood and adolescence

• Become familiar with the importance of positive relationships, experiences and environments to developing adaptive responses to stress and change in children and young people

• Understand that mental disorder in childhood is a dimensional phenomenon

• Learn nursing skills that help promote good mental health and enhance resilience in children and young people
Introduction

The focus of this chapter is the role of the nurse in optimising child and youth mental health. An overview of mental disorders experienced during childhood and adolescence is followed by a discussion of mental health promotion for children and young people. In this edition, we have included a section on eating disorders. Although the lifetime prevalence of these disorders is very low, they are common, and nurses play an important role in the care of those affected children and young people admitted to hospital for treatment. The importance of working closely with the parents and families of children and young people disabled by mental illness and the services available to them is emphasised throughout the chapter.

The Australian Institute of Health and Welfare (AIHW) published the first national survey of child and adolescent mental health and wellbeing in Australia in 1998. The second survey was published in 2015 (Lawrence et al., 2015); it includes data on the use of mental health services by children, young people and their families. This national survey of mental health and wellbeing provides valuable information on the prevalence of child and youth mental disorders in Australia. The AIHW also publishes a list of services that exist for people living with a mental disorder and makes recommendations for services that are needed. The latest survey indicates that while the prevalence of mental health disorders for children and young people remained stable between 1998 and 2015, there was a significant increase in the use of mental health services for 4–17-year-old Australians. In summary, 14 per cent of children aged 4–17 years in Australia experienced mental health problems – 16.3 per cent of boys and 11.5 per
cent of girls (Lawrence et al., 2015). More detailed data are available from individual states in Australia and published by the Australian Bureau of Statistics. These are referred to within the chapter.

**Mental health problems and mental disorders**

The extent to which children and young people experience symptoms and/or behaviours that cause problems to parents, teachers, peers and society in general varies. Assessment over time is necessary to distinguish the type, frequency and severity of disruption. Many children who are referred for treatment do not have symptoms that meet the criteria for a mental disorder. This does not mean that the symptoms and behaviour may not meet the criteria at another point in time, however. The cutoff point between those who receive a formal diagnosis and those who do not is arbitrary. How mental disorders, and mental health and wellbeing, are defined is important:

Mental health is a state of well-being in which individuals can realise their abilities, can cope with the normal stresses of life, can work productively and fruitfully, and are able to make a contribution to their community … Conversely, mental health problems can affect perceptions, emotions, behaviour and social well-being. Mental disorders, as distinct from mental health problems, are characterised by a clinically recognisable set of symptoms or behaviours that interfere substantially with social, academic or occupational functioning … Different types of mental disorders consist of a different combination of symptoms that may differ in severity.

(AIHW, 2009: 30)
Changes to the way in which children and young people are diagnosed and assessed for mental disorders were made in the 2013 version of the manual published for this purpose, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (APA, 2013). The fifth edition of the DSM saw significant changes that affected the ways in which children and young people were diagnosed and assessed for mental disorders. For children diagnosed prior to the release of DSM-5, no change was made to a diagnosis of mental disorder. Notwithstanding this, the ways in which bipolar disorder, Attention Deficit Hyperactivity Disorder (ADHD) and autism are assessed in children and young people have changed quite significantly.

Disorders are presented in DSM-5 according to age, gender and developmental characteristics. The first section of this chapter focuses on those childhood conditions commonly experienced in health-care settings in which paediatric nurses practise. While not an exhaustive list of the conditions experienced in childhood, they are the conditions that experienced the most intense research and scrutiny during the period leading up to the release of DSM-5. These are Autism Spectrum Disorder (ASD) and ADHD.

To better understand these changes, the first section of this chapter details selected mental disorders of children and young people. How children’s social, behavioural and emotional symptoms are categorised and diagnosed is important to how they are treated. Diagnosis is complex, and the child’s development and its trajectory must be considered. For example, some behaviours demonstrated by a 14-month-old infant are acceptable, whereas if the same behaviours continue through to the child’s second or third birthday, this may be reconsidered and the behaviours could indicate a mental disorder.
General paediatric nurses in Australia are not responsible for the
diagnosis of mental disorders in children, but understanding is crucial.
Mental health and wellbeing are essential components of a paediatric
assessment. The majority of child and adolescent mental disorders are not
seen in paediatric hospitals. When they are, they are usually comorbid with
a physical health problem or the result of self-harm. They may also result
from a physical health problem (see Chapter 4) and be missed altogether.
Child and youth mental health services are offered within hospitals and
other community settings, but children with mental disorders also present
to paediatric services for a range of reasons other than their mental health
care. For this reason, it is important to understand disorders of children and
young people, and the ways in which they are best managed for optimal
care in the paediatric environment.

Children’s development is a dynamic process. A child’s mental health
is viewed in the context of their development and maturation overall,
rather than being a single element or achievement at only one point in
time. It is important to establish those behaviours that are limited and those
that are persistent. Focusing on a single aspect at one particular time is of
little value in appreciating the complete clinical picture, and often leads to
incorrect assumptions. Diagnosis not only occurs over time; it also
depends on the level of disruption to the child’s biopsychosocial
development and integration into the wider world – that is, it is a
dimensional phenomenon. Cognitive, emotional and psychological
development during childhood and the adolescent years occurs in a
predictable sequence but is unique to each person. This is taken into
consideration when assessing children and young people’s mental health.

What mental disorders affect Australian
children?

As previously mentioned, the second survey of national prevalence data for Australia’s children and young people was published in 2015 (Lawrence et al., 2015). The Diagnostic Interview Schedule for Children Version IV (DISC-IV) was used to measure mental disorders over the 12-month period preceding the survey. Data were collected from parents for children aged from 4–17 years as well as from young people aged from 11–17 years to allow for analysis within and between age groups as well as sex. The data indicated high levels of mental health problems for both girls and boys as well as for young people up to the age of 17 years.

The data revealed a prevalence of one in seven (13.9 per cent, or 560,000) Australian children and young people experiencing at least one mental health problem in the preceding 12 months. Rates for girls were lower (11.5 per cent) than for boys (16.3 per cent). ADHD was the most common disorder for boys aged from 4–11 years (10.9 per cent) and from 12–17 years (9.8 per cent); interestingly, for girls the prevalence halved from 5.4 per cent from 4–11 years to 2.7 per cent from 12–17 years. Differences in the prevalence of Major Depressive Disorder were found between adolescent girls (5.8) and boys (4.3), but not for those aged 4–11 years (Lawrence et al., 2015).

**Attention Deficit Hyperactivity Disorder**

<table>
<thead>
<tr>
<th>Case study 7.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Larry</td>
</tr>
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</table>
A 9-year-old boy, Larry, was admitted to the children’s orthopaedic ward three weeks ago for elective surgery. He had a left leg lengthening procedure to correct a congenital anomaly the day after admission. A Taylor Spatial Frame (leg-lengthening mechanism) has been applied and, apart from physiotherapy sessions, he is on complete bed rest. Larry’s mother Kim attends to his care each day between 7.00 am and 8.00 pm, and he sleeps well between his mother’s visits. Yesterday, Kim pressed the buzzer several times in succession to call for emergency assistance. Larry was found thrashing around the bed, pulling at his leg-lengthening device, screaming incoherently and violently responding to his mother’s requests to calm down.

Kim is shocked and distressed. The staff are unable to calm him and the psychiatric referral team is called in. Larry is prescribed a paediatric dose of anti-psychotic medication and finally settles down to sleep. Ongoing care by the psychiatric team is commenced. Following the event, Kim confides that Larry was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) at the age of 7 and was taking medication for about six months to treat the symptoms until a few months ago. On the medication, he had been able to concentrate better at school and his academic functioning had improved, but Kim disliked the perceived side-effects of the medication and was concerned it would lead to drug addiction in the future. She confides to the nursing staff that she has been following a parenting intervention under the guidance of a psychologist. The program seems to have worked very well, with noticeable improvement in Larry’s behaviour and emotional regulation. But this makes Kim feel overwhelmed with guilt.
Given the success of the program, Kim believes that her parenting style must have caused the condition.

ADHD is the most prevalent child mental disorder, not only in Australia but worldwide (Riglin et al., 2016). Children present with inattention, hyperactivity and impulsivity and, compared with their normative peers, have poor learning ability, low academic outcomes and social incompetence. There are three sub-types of ADHD: inattentive; hyperactive impulsive; and combined. Symptoms can persist into the adult years (Riglin et al., 2016).

ADHD is a complex disorder that is difficult to manage well. Nursing interventions to encourage comprehensive evaluations are valuable because management needs to be based on comprehensive neuropsychological and psycho-educational assessments. This not only determines the diagnosis, but also establishes the existence of any potential comorbid conditions (Feldman & Reiff, 2014). Comorbidity is common with this disorder and occurs in as many as two-thirds of children with ADHD. Comorbid conditions include learning disabilities, Conduct Disorder, Oppositional Defiant Disorder (ODD) and anxiety (Sawyer et al., 2016). Almost half (45 per cent) have comorbid learning disabilities, placing them at risk of poor educational achievement and potentially low socioeconomic status (Grizenko et al., 2013). Furthermore, poor academic self-concept is associated with the development of anti-social behaviours. Children with the inattentive type of ADHD tend to have the greatest academic failure rates and do poorly at mathematics in particular (Grizenko et al., 2013).

**Nursing assessment and interventions**
As discussed in Chapter 4, the perspectives of parents and carers, and their willingness to engage in positive health behaviours for the child, determine outcomes. In this case scenario, the nurse has the chance, through crisis, to assist the mother, Kim, to establish the best way forward in managing Larry’s symptoms and behaviour (Becker, Goobic & Thomas, 2009). With Larry as an inpatient in hospital, the paediatric nurse has a window of opportunity to encourage comprehensive evaluations, discuss school advocacy and support services, and reinforce the benefits of changing parenting style and the home environment in ways that may benefit her son (Becker, Goobic & Thomas, 2009). It is of utmost importance in this case scenario to emphasise that treatment success does not infer aetiology. There are no known causes of ADHD. However, it is common for parents to believe that their parenting is to blame, especially after the success of parenting interventions that modify parenting style. Guilt and shame are also common among parents of children with ADHD, as there is a genetic predisposition, with one or both parents often having the same features (Riglin et al., 2016).

Parenting interventions that focus on child behaviour management have proven to be somewhat successful. If implemented correctly, these have been reported to reduce the main symptoms of ADHD in both the short and longer term (Hoath & Sanders, 2002). Importantly, they can improve parenting satisfaction and confidence. At the same time, it is important to emphasise that behaviour management is not as effective as medication, and medication is especially successful in raising the likelihood of academic success and school completion (Grizenko et al., 2013). These outcomes bode well for the child’s trajectory into adult life.

The safety and effectiveness of non-stimulant drugs and long-acting methylphenidate and amphetamine medications have been demonstrated in research conducted over the past two decades (Feldman & Reiff, 2014).
Parents do remain reluctant to medicate their children for ADHD, despite obvious behavioural and academic improvements when treated by psychostimulants (Grizenko et al., 2013). Longer-term effects of medication for ADHD are not well understood at present. For Larry and Kim, the added burden of a physical disability (one leg has been shorter than the other since birth) would no doubt impact the way in which they perceive the treatment options for ADHD.

Larry is at a vulnerable stage of development. At 9 years of age, he is likely to be able to recognise cultural and individual differences and may be struggling to come to terms with his problems of inattention, hyperactivity and impulsivity (Erikson, 1968). Impairment of academic performance and social isolation have the potential to interfere with any sense of accomplishment, important to children of his age.

The nurse can assist by recommending:

- comprehensive psychosocial and psychoeducational assessments
- consultation and regular follow-up with a paediatrician for monitoring and modification of medication
- re-engagement with the behavioural parent training program
- support and counselling services, including school support (Feldman & Reiff, 2014).

**Reflection points 7.1**

- A high proportion of children and young people – boys and girls – report mental health problems in Australia.
- Behavioural and emotional changes and changes in function should be referred immediately and appropriately.
Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong developmental disability featuring deficits in social communication and social interaction with repetitive patterns of behaviour, interests or activities (APA, 2013). The prevalence rate is estimated to be from 5.7 to 21.9 per 1000, with boys more commonly affected than girls (CDCP, 2014). In the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000), DSM-IV, children with ASD were categorised as having one of: autistic disorder; Asperger’s Disorder; or pervasive developmental disorder not otherwise specified (PDD-NOS). With the release of DSM-5, these are all now referred to as a single condition, ASD. This is an important change because, for some children, one of the former categories may still be used. As previously mentioned, DSM-5 relates to diagnoses made since its release in 2013, meaning that children will continue to have a diagnosis of Asperger’s Syndrome. ASD also has a severity rating of 1, 2 or 3, depending on how much support the person needs. Some people have mild symptoms while others have more severe and pervasive disability (APA, 2013).

ASD is characterised by the child having difficulties in each of two areas: deficits in social communication; and fixated interests and repetitive behaviours. Deficits in social communication include poor social interaction and limited use of language to communicate. Some children
will not speak at all, not respond when spoken to and not join in with others’ actions and activities. The second area – fixated interests and repetitive behaviours – can obviously only be observed as the child grows and certain developmental milestones are not met. Having narrow and intense interests is more obvious as the child goes to school and is expected to become involved in others’ interests and games. Sensory sensitivities are also characteristic. The child may choose to only wear one type of fabric, may dislike labels on clothes or have particular bedding preferences. One of the most difficult manifestations is the desire to eat only certain foods with a specific texture or colour.

It is critical to be able to diagnose ASD in early childhood so that early intervention can be implemented. There are a number of successful evidence-based programs available, targeted to the way in which ASD presents in the individual child. Critical decisions about schooling need to be made early, as there need to be adequate mechanisms of support to optimise learning ability in children with ASD. These decisions should be revised regularly, with reflection on the most appropriate context for learning.

Transition to high school – and indeed to adult health and educational services – needs to be planned carefully in advance.

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**Case study 7.2**

**Benjamin**

Benjamin, who is 10 years old, was diagnosed with ASD at the age of 6. ASD affects his ability to communicate, his behaviour and his ability to engage with and relate to his peers. Benjamin attends an Aspect school in New South Wales, which provides an individualised program of education for children with ASD. In this
learning environment, the specific social and educational needs of children with ASD are catered for. Benjamin’s parents are well supported in their community. They are members of a community support group of parents with children with ASD and have access to government assistance to help meet Benjamin’s complex needs. Early diagnosis and multidisciplinary early intervention have assisted Benjamin to develop skills to help him become as independent as possible in the wider community. The Aspect schoolteachers have recommended that Benjamin attend the Child and Adolescent Mental Health Service for assessment. They are concerned about Benjamin’s mental health and wellbeing. Symptoms of anxiety and depression are common comorbid conditions to a diagnosis of ASD and appear to be impeding his academic progress and limiting his engagement with teachers and peers.

**Nursing assessment and interventions**

Be sensitive to the way in which Benjamin is experiencing the world. For example:

- Listen to his parents’ concerns and provide accurate information.
- Acknowledge that the clinic setting is unfamiliar and therefore potentially highly stressful to Benjamin.
- If he becomes an inpatient, work closely with his parents to establish structure and routine.
- Understand the ways in which he communicates discomfort and anxiety.
**Reflection points 7.2**

- Because nurses will encounter children and young people with ASD across a wide range of services, it is essential to become familiar with what ASD is, to understand how to identify children with ASD and to understand how a formal diagnosis is made.
- Anxiety, depression and dissociative responses to stress are comorbid conditions to ASD.

**Externalising disorders: Conduct disorders**

**Oppositional Defiant Disorder and Conduct Disorder**

**Case study 7.3**

**Jack**

Jack’s mother has an appointment at the GP clinic to see the practice nurse about her son’s increasingly disruptive behaviour. She reports that Jack, who is 12 years old, has developed a terrible temper and becomes easily agitated and aggressive for trivial reasons. His anger is especially targeted towards his mother, and she is becoming quite fearful of him, both for herself and for his 7-year-old sister. He had been a happy young child full of energy and fun, but his moods are now unpredictable. In fact, he is quite destructive around the home and at school. He refuses to follow
instructions and deliberately sets out to be argumentative. His teachers at school have been calling her to the school two or three times a week for behaviour-management planning in response to him becoming too difficult and disruptive for them to manage. They have suggested that she bring Jack in for assessment and treatment.

Jack’s disruptive behaviour has escalated to the point where his behaviour is causing problems for his parents, teachers, peers and society in general. Many children are referred for treatment of disruptive behaviour. It is important to have the child assessed and to implement strategies as soon as possible to reverse the conduct problem because severe cases frequently continue to adulthood as Antisocial Personality Disorder or other adult mental health problems (Erskine et al., 2016).

Conduct Disorder (CD) is a formal term used to identify a subset of disruptive children who present with severe and persistent behaviour problems (APA, 2013). Oppositional Defiant Disorder (ODD) is diagnosed when the child is repeatedly argumentative, loses their temper easily and has issues with anger and resentment. These behaviours vary in frequency and severity, and diagnosis tends to be arbitrary. The problems they cause can affect parents, teachers, peers and society in general. CD is much more extreme, and features a child who violates the rights of others, is aggressive and is deliberately cruel to other people or animals.

Until recently, the research conducted in this field was gender biased because of the high rates of CD found in boys. However, this has now been reversed, and the trajectory for girls’ mental health and wellbeing is starting to attract attention. Adolescent onset of CD in girls shares a similar trajectory towards adult psychopathology and criminal activity as
childhood onset CD – that is, that early onset of CD is associated with a poorer prognosis. On the other hand, adolescent onset of CD in boys tends to be adolescent limited – that is, they are likely to grow out of their conduct problems (Kjeldsen et al., 2016). This is an important finding because it points to the need to pay more attention to CD that develops in the adolescent years, especially for girls.

Not all children who meet the criteria for CD will become chronic offenders as adults, but the risk is high. Parents need to be motivated and engaged to contribute to the parenting interventions available. This requires regular feedback and consultation to keep them on track with a tailored program that meets the needs of their child. Institutionalisation and other forms of group-based treatments are not advised due to the strengthening of deviant behaviours through group pressure. Parents may feel that they need respite, but if possible the best approach is to modify their interactions with the child to reduce the severity of the child’s conduct problems (Dadds & Fraser, 2003).

### Reflection points 7.3

- Family interventions show the most promise of success.
- Disruptive behaviour patterns become more resistant with age.
- Early intervention and prevention are needed.

### Risk and protective factors

A number of developmental characteristics or events are associated with the onset of mental problems in children and young people. The worst
outcomes result from the cumulative effects of multiple risk factors acting on a single child. These risk factors overlap and place the child at risk for both internalising (anxiety and depression) and externalising (CD, ODD) disorders. Thus the same risk factors can be identified for each (McLaughlin et al., 2012). Risk and protective factors are presented in Table 7.1.

**Table 7.1** Risk and protective factors for mental health problems in childhood and adolescence

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Protective factors</th>
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<tbody>
<tr>
<td>Child factors</td>
<td></td>
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<tr>
<td>Genetic risk</td>
<td>High intelligence</td>
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<tr>
<td>Brain damage</td>
<td>Good general health</td>
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<tr>
<td>Low intelligence</td>
<td>Engaging temperament</td>
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<tr>
<td>Difficult temperament</td>
<td>Good social skills</td>
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<tr>
<td>Poor social skills</td>
<td>High self-efficacy</td>
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<tr>
<td>Low self-esteem</td>
<td>High self-esteem</td>
</tr>
<tr>
<td>Parenting and family factors</td>
<td>Poor-quality relationship with parents</td>
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<td>-----------------------------</td>
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<tr>
<td>Insecure attachment style</td>
<td>Secure attachment style</td>
</tr>
<tr>
<td>Harsh, inflexible or inconsistent discipline</td>
<td>Fair, consistent discipline with clear boundaries for behaviour</td>
</tr>
<tr>
<td>Inadequate supervision</td>
<td>Strong involvement with child</td>
</tr>
<tr>
<td>Parental conflict</td>
<td>Domestic harmony</td>
</tr>
<tr>
<td>Parental psychopathology</td>
<td>Good mental health of parents</td>
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<table>
<thead>
<tr>
<th>School factors</th>
<th>Bullying</th>
<th>Strong school culture of support</th>
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</thead>
<tbody>
<tr>
<td>Poor resources</td>
<td></td>
<td>Good supervision</td>
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An interacting systems approach is a useful framework for understanding the many risks and protective factors that influence mental health. Bronfenbrenner’s (2001) bioecological model of human development provides a strong framework for this. The bioecological model also provides a useful framework for assessing and treating children who experience mental illness and their families (Taylor, 2003). This perspective has a strong focus on strengthening proximal processes (introduced in Chapter 2) and supportive environments to optimise development. It is important for paediatric nurses to develop a strong nurse–child relationship, and to allow time during nursing care for the relationship to develop. A strong nurse–child relationship is a protective factor against the mental health challenges that can arise for child and youth during health care. Various indicators of the ecology influencing child and youth mental health are presented in Table 7.1.

**Internalising disorders: Anxiety and depression**
A significant research effort has been conducted to date with regard to risk and protective factors for child and youth mental health. Particular attention has been paid to the influence of maternal depression and to a lesser extent paternal depression on child mental disorders. More research is needed to disentangle the relationships between these complex concepts. Children and adolescents experience anxiety disorders, such as phobias, social phobias and generalised anxiety disorder, in a similar way to adults. Separation anxiety disorder is specific to childhood, and is characterised by extreme anxiety when separated from home or the parent. The child may experience a sense of overwhelming panic. Psychodynamic, behavioural, cognitive and family therapies have demonstrated success in managing anxiety in childhood (Bennett et al., 2013; In-Albon & Schneider, 2007).

There are similar explanations for both child and adult depression. These include loss, learned helplessness, negative cognitions, and low serotonin and norepinephrine activity in the brain. Young children are likely to have comorbid separation anxiety, phobias, somatic complaints and behaviour problems. The diagnosis for paediatric depression relies on the ability of the child or their parent to report on the internal affect of the child. Depressed mothers may also over-report depressive symptoms in their child, although a transactional approach to child development suggests that the child’s characteristics exacerbate the maternal psychopathology (Sameroff & MacKenzie, 2003) – that is, a mother is more likely to be depressed if her child exhibits symptoms of mental health problems. Moreover, a healthy father appears to mediate the relationship between maternal depression and child psychopathology, whereas a child with both parents affected by mental illness is at high risk of childhood depression and other disorders (Goodman et al., 2011).
A number of adverse outcomes may result from childhood mental disorders and poor mental health. These include general suffering, functional impairment, stigma, discrimination and even premature death (McLaughlin et al., 2012). Given the importance of community-based early intervention and prevention approaches to developmental disruption, and children’s and young people’s mental health and wellbeing, this chapter now focuses on the importance of promoting mental health.

Reflection points 7.4

- Nurses work with children and young people in a range of settings, including the mental health and youth justice systems within Australia.
- Promotion of mental health and wellbeing for children and young people has a place in all settings, not only child and adolescent mental health services or the youth justice system.
- Children and young people’s mental health problems affect the health and wellbeing of their families and communities.
- A number of developmental factors contribute to the onset of mental disorders in children.

Promoting mental health in children and young people

Case study 7.4
**Jason**

As a paediatric nurse at the local rural hospital, you meet Jason, a 16-year-old male admitted for investigations related to abdominal pains and weight loss. Jason has recently been discharged from hospital following an appendicectomy. His previous admission was uneventful; however, Jason now discloses to you that he has been feeling down lately and has been ‘having trouble’ at school. Until recently, Jason would have been described as an enthusiastic school student. Now he is noticeably withdrawn, increasingly alone at lunchtime and not participating in class or after-school and weekend activities. There are concerns that Jason is being bullied.

Jason is an only child, and lives with his mother who is employed mainly after hours as a cleaner. His father left the family when he was a baby and Jason has had no contact with him since. Jason and his mother have always been close, but recently Jason has seemed more distant to her.

When you meet with Jason, he spends some time telling you about his life up to this point. Over the next few days, you develop a rapport with Jason and see from his body language and conversation that he is becoming more comfortable. You speak to him about his concerns and give him an opportunity to talk about what he believes has been happening. He says he has always been bullied and it hasn’t really bothered him. Now some boys at school have started to torment him for not joining in contact sports. The town’s footy team, for which Jason’s father once played, has a long history of winning the regional competition and the community supports the team passionately. Jason shares that he is becoming frightened that these torments will turn violent. Jason’s passion in life is dancing. When he is older, he hopes to be able to attend...
dance classes in the city but at present his mother can’t afford the fees.

**Determinants of child and adolescent mental health**

Mental health is defined as

the ability to cope with and bounce back from adversity, to solve problems in everyday life, manage when things are difficult and cope with everyday stressors. Good mental health is made possible by a supportive social, friendship and family environment, good work–life balance, physical health and, in many instances, reduced stress and trauma.

(Procter et al., 2013: 4)

This wonderful definition highlights the importance of bioecological factors and how they coalesce to promote an adaptive response to life challenges and resilience across the lifespan (Masten, 2014). Recent advances in understanding the determinants of developmental health and neuroplasticity have led to an awareness that much can be done to promote positive mental health in children and youth, resulting in a positive impact in life outcomes. Through enhancing early life experiences and strengthening the supportive pathways during childhood and adolescence that help develop mental health, many determinants associated with mental illness can be reduced substantially (Fox et al., 2015)

The availability and increased use of mental health services reported earlier by Lawrence et al. (2015) reflects a recent trend in Australian health-care services towards strengthening support and early intervention, especially in promoting mental health. One key to enhancing mental health
is early intervention with children and young people through frameworks such as the Common Approach (see Box 7.1). The Common Approach (ARACY, 2016) is gaining support from Australian government departments. For example, in Tasmania the government accepted and is working towards a whole-of-government implementation of Recommendation 2 from the 2016 Redesign of Child Protection Services Tasmania. Strong Families. Strong Kids report:

That the Tasmanian Government and non-government services work together to implement and embed the Common Approach framework across the service system to increase the capacity of practitioners in first contact with children and families to identify both their strengths and needs, build on these strengths within families, and link families with the supports they need before problems escalate into crises.

(DHHS, 2016: 8)

**Box 7.1  The Common Approach**

The Common Approach, developed by the Australian Research Alliance for Children & Youth (ARACY, 2016), is a flexible framework to help all professionals have quality conversations with young people or families about all aspects of their wellbeing, including aspects that fall outside the professional’s usual area of work (see Figure 7.1). It aims to support children and young people at a universal, preventative level, and to be accessible to everyone who interacts with young people. It is designed not only to be adaptable to a wide range of situations, but also to provide a common language and approach that can support collaboration across sectors (ARACY, 2016: 1).
At the centre of the Common Approach is a useful tool for use in practice: the Wellbeing Wheel (see Figure 7.2). The Wellbeing Wheel provides a visual and holistic view of a child or young person’s life, based on the ecological model of child development. It covers six broad domains of wellbeing: physical health, mental health, relationships, material basics, learning and safety.
The Wellbeing Wheel includes discussion prompts in each domain that are based on common indicators of areas of potential strength or need (see prompts in Figure 7.2). Practitioners are required to be trained in the Common Approach, to apply the method and to access the resources. Full implementation of the Common Approach in organisations is negotiated through ARACY or through the relevant state government department currently implementing the Common Approach in its jurisdiction. A focus on holistic wellbeing in childhood promotes mental health and recovery from mental illness.

The majority of children progress into independence and adulthood well. Their mental health is the foundation of their capacity to thrive throughout life. They have discovered the keys to adapting to the
challenges and stresses that face all children and adolescents. Unfortunately, far too many children are exposed to toxic stress – chronic over-stimulation of the stress-response system – and experience limited or ineffectual support during transition periods. Young people who are at risk of declining mental health frequently lack the opportunity to experience safe and supportive environments where they feel loved and secure, and consequently are disengaged from education, family and/or their community (NSCDC, 2012a; O’Donnell et al., 2012; Tomyn, 2013).

One challenge in promoting mental wellbeing is the lack of useful indicators and associated health statistics. Wellbeing measurements, including mental health, have only recently been considered. Such measures are different from biological and epidemiological measures, which tend to measure disease and risks. Wellbeing measures tend to be multifactorial, considering sociological, emotional and even at times spiritual indicators using ordinal and qualitative data. ARACY and the AIHW are at the forefront of developing wellbeing measures for children and young people. For example, ARACY’s Report Card (ARACY, 2013a) aims to report positive measures of wellbeing; however, many available indicators remain risk oriented. The goal for indicators of ‘positive family functioning, positive mental health, and social and emotional development is balanced by the realities of the available data, therefore negative measures such as family conflict, suicide rates, psychological distress and violence need to be used’ (ARACY, 2013a: 3).

The inaugural Australian Youth Development Index (YDI) is based on 16 key indicators measuring youth development. Although the ‘development of mental health is integral in the prevention of depression, anxiety and low self-esteem’ (Youth Action, 2016: 25), an established set of indicators related to mental health remains absent. The YDI reports Australia ranked third out of 185 countries for the 2016 Global YDI.
Despite this overall achievement, inequitable gaps in outcomes are evident. For example, in the area of mental health, the Aboriginal and Torres Strait Islander youth male suicide rate is ‘higher than any national rate reported for any country in global reports’ (Youth Action, 2016: 22).

In the Mission Australia 2015 Youth Survey (Cave et al., 2015), young people aged 15 to 19 years ranked the top three issues of concern as coping with stress, school or study problems, and body image, and the two most highly valued attributes as friendships and family relationships. Understanding what concerns children and young people can help guide discussions exploring their mental health and signify where mental health promotion may be required. Paediatric nurses can contribute to promoting mental health by asking young people how satisfied they are with these aspects in their life. Paediatric nurses also promote child mental health through supporting the child’s family when embedding a bioecological model of human development, empowerment and family partnership in their family-centred care practices. Supporting families of children who are ill allays their distress, increasing the family’s capacity to care for their child (Tallon, Kendall & Snider, 2015).

**Promoting resilience and positive adaptive responses in children and adolescents**

Resilience is defined as ‘the capacity of a dynamic system (such as a child or family) to adapt successfully to disturbances that threaten system function, viability or development’ (Masten, 2014: 6). It is the application of a systems framework into a functional model. Child and youth mental health is dependent on developing adaptive skills fundamental for resilience. Adaptive skills can be learnt especially well during childhood, while the brain has the most capacity for plasticity. One evidence-based
factor that it is important for paediatric nurses to cultivate and that helps children build resilience is supportive adult–child relationships, such as the nurse–child relationship. It is important to our work in paediatric nursing to understand that resilience programs for children and young people have been linked to improved mental health in children and youth (Khanlou & Wray, 2014).

In recent years, ARACY has been conducting extensive research to identify the best evidence for the promotion of child and youth wellbeing. This evidence is summarised in an extensive array of evidence-based summaries and reports available freely online at www.aracy.org.au. In a ground-breaking Australian first, ARACY has collated this information and developed a national plan for child and youth wellbeing, the Nest action agenda (ARACY, 2013b). The Nest action agenda strives to provide a framework for promoting child and youth wellbeing, including the mental health of children and young people. Three domains of the Nest applicable to promoting child and youth mental health are:

- being loved and safe
- promoting positive participation
- fostering a positive sense of culture and identity.

**Being loved and safe**

A positive relationship with parents or caregivers is the first step towards children and youth being loved and safe, and maintaining mental health. However, the need for children and youth to be loved and safe is a whole-of-community responsibility. The past failure of Australian institutions involved in child and youth services to protect children and young people from abuse have been documented extensively (see the Royal Commission
into Institutional Response to Child Sexual Abuse website, www.childabuseroyalcommission.gov.au). The testimonies of child abuse victims provide examples of the magnitude of mental, physical, emotional and spiritual distress that can result from children and youth not being loved and safe in the community. When abuse occurs – in the family or in the community – the shattering of love and safety can pervade the child’s life and substantially reduce mental wellbeing. Noble-Carr, Barker and McArthur (2013: 19–20) report that young people who experienced abuse most often [struggled with] long-lasting emotional pain, disillusionment and a negative view of the world, which sometimes resulted in shutting oneself off from the world … [they] experienced feeling alone, or even suffering from agoraphobia … leaving them alone to overcome very negative perceptions of themselves and the world around them.

Their mental health is compromised by the abuse. The first strategy to promote mental health is to foster a loving and safe ecology for children and adolescents both in the home and in care. This may include early notification and referral of families in need of support. Such nursing action can enhance the nurse–family relationship by demonstrating a commitment to the rights of the child and support future mental health-promotion strategies (see the case study resolution and the responsibility to report child maltreatment section in Chapter 2).

Developing child and youth mental health is everyone’s responsibility, and begins during the antenatal period. The wellbeing of parents – particularly mothers – influences the early life experiences of the developing child. A child’s interactions with parents and those around them from birth establish the foundation for mental health (AIHW, 2012). Investing in services that support parents’ wellbeing is also an investment
in the mental health of children and adolescents. Nurses caring for children also have a role to play in caring for the family. If the child’s experience includes maternal/familial deprivation and toxic stress, the healthy development, mental wellbeing and life chances of the child can be adversely affected. The experience that appears to have the most potent influence on promoting mental wellbeing for children and youth, and that promotes development of neural pathways and functioning, is being involved in a positive, loving and safe relationship with others from birth and throughout early childhood. Such positive early life interactions are called ‘serve and return interactions’ (NSCDC, 2012a; Noble-Carr, Barker & McArthur, 2013). It is well recognised that children can and do experience mental health problems, and early intervention and support can have a significant positive effect on the development of future mental health and resilience (NSCDC, 2012b, 2015).

As a result of this knowledge, many schools around Australia put significant effort into developing and maintaining environments that are safe and nurturing in order to foster positive mental health. The Mind Matters program, which is gaining momentum within the Australian high school setting, is a good example of this. Mind Matters involves the implementation of a whole-school program targeted at supporting young people and promoting mental health. It aims to strengthen collaboration between school students, staff, parents and community support agencies by supporting those networks to move towards targeted goals within the specific environment. It provides training for all levels of staff to increase awareness and understanding of the importance of mental health support and promotion for young people (Wyn et al., 2000; see www.mindmatters.edu.au). In Case Study 7.4, Jason experiences some challenges and strengths in being loved and safe. Safe and loving family relationships have provided the support Jason needed in the past to
withstand bullying without his self-esteem being undermined. However, promoting Jason’s mental health will also require ensuring a safe ecology at school.

**Promoting positive participation**

During childhood, positive participation is fundamental to positive learning experiences and personal development, with significant benefits such as increased confidence and self-esteem in young people (ARACY, 2013b). Positive family, peer, classroom and community engagement can be encouraged by including children and youth in decision-making, especially in matters that affect their health and any health care they may require (see the section on participation rights in Chapter 2). Participation through technology for social connection and influencing public opinion are newly emerging areas that require further research to determine the relationship with positive mental health outcomes. Marginalised and disengaged young people experience higher rates of social and mental health problems. Youth participation in decision-making and activities that develop personal skills, along with institutions that offer opportunities for positive experiences, have a positive effect on young people feeling valued, and promote mental and social health (ARACY, 2008). Pregnant teenagers and young mums are one example of a group that can be marginalised and at high risk of disengaging from institutions, such as education systems, which can potentially have a positive impact on their mental health. Young mums and their babies are at long-term risk of low educational achievement and low income, which impacts negatively on mental health (AIHW, 2012). There are numerous innovative programs within communities and schools around Australia that aim to keep young mothers engaged in either education or workforce planning and/or
participation in order to promote good mental health and increase positive outcomes for these young women and their babies.

**Fostering a positive sense of culture and identity**

Evidence from resilience and positive youth development research and literature conclusively demonstrates that children and youth develop a positive sense of themselves when they experience positive enduring connections with the people and services around them. Factors found to influence young people’s development of a positive sense of identity, purpose and meaning in life are:

- positive, caring connections with others
- opportunities to participate in meaningful activities and/or contribute to their communities (through sport, study, work, youth groups, church groups, music groups, volunteering or caring activities)
- being acknowledged for being good at something
- finding a sense of belonging to a place or group (via family, cultural group or church)

Young people question who they are in relation to those around them, and where they have come from. Strengthening understanding of family and cultural traditions fosters personal awareness and a sense of belonging. Young people who are disconnected from school, education, employment, their family and the community report lower personal wellbeing compared with youth who are connected in meaningful ways (Tomyn, 2013). In
modern Australian society, there are many factors that impact the success of passing on traditional beliefs, and young people not forming a connection with their culture. Maintaining Jason’s positive sense of connection to his family, school and community through supporting his passion for dancing and giving him opportunities to participate in this activity may be a way of strengthening his positive sense of identity. The school could explore how Jason could represent it at dancing events previously not engaged in by this community.

**Eating disorders**

* Managing disordered eating and eating disorders experienced in childhood and adolescence

Disordered eating is an emerging challenge influencing life outcomes for children and young people. This term encompasses both the concepts of body image – including conformity to cultural standards and body dissatisfaction – and body weight management – including nutrition, obesity, restrained and binge eating. At the centre of disordered eating is the child or young person, their biological growth requirements and their relationship with their context or environment, which influences their eating behaviour. Nurses caring for children and young people experiencing disordered eating must move beyond considering individual factors and encompass multiple contextual influences related to the presenting eating disorder (Harris, 2015). The *Child and Youth Health Practice Manual* simply identifies ‘the difference between disordered eating and eating disorders is the frequency and severity of the associated behaviours’ (Queensland Hospital and Health Service, 2014: 242).
Eating disorders can quickly become life-threatening and need to be taken very seriously once identified in children and young people. Management requires an individualised approach to treatment and nursing care. Eating disorders are not exclusive to childhood or adolescence, nor are they one-dimensional. Indeed, eating disorders may be experienced across the lifespan. For children and young people, the best evidence available indicates that family-based treatments should be applied to prevent the very serious mental and physical health outcomes in which eating disorders can result (Jewell et al., 2016).

Anorexia Nervosa (AN) and Bulimia Nervosa (BN) are two common eating disorders seen in paediatrics. They are also the eating disorders that have attracted the most research and treatment attention to date. AN features extremely low weight for age, distorted body image and fear of weight gain. BN features binge eating/purging cycles with the intense fear of weight gain (APA, 2013). Treatments for both include family therapy and multifamily therapy (see Jewell et al., 2016 for a comprehensive review of the literature). According to Jewell and colleagues (2016), key elements of treatment are:

- an inclusive, family approach
- a parents as therapist approach
- externalisation of the disorder.

Treatment is complex, requiring specialist skills. Paediatric nurses knowledgeable about disordered eating and eating disorders can significantly help promote healthy eating in children and adolescents. Key health-promotion strategies recommended in the Queensland Child and Youth Health Practice Manual for body dissatisfaction and disordered eating include promoting positive cultural and social messages, addressing
personal characteristics of the individual and promoting self-esteem and strong family/social relationships to strengthen resilience. Evidence does not support simply talking about causes, symptoms and outcomes as being effective prevention or treatment technique, however (Queensland Hospital and Health Service, 2014: 242–3). Paediatric nurses’ relationship with children and young people diagnosed with AN is itself health promoting, and is one key aspect of the recovery process (Salzmann-Erikson & Dahlén, 2016). These key elements of treatment and health promotion all align with the Common Approach Framework presented earlier in this chapter.

**Ten practical strategies for promoting child and adolescent mental health**

Evidence-based strategies for promoting mental health of children and youth have been identified recently through extensive reviews. These strategies can be summarised in a list that provides guidance for promoting mental health through paediatric/child health nursing care in a facility or the community:

1. Be encouraging and focus on strengths, both initially and throughout the care, with a focus on skills development. For example, encourage the young person to identify personal strengths and discuss how these strengths might be used to enhance their mental wellbeing. Identify existing barriers to good mental health and introduce specific skills that may help to avert the potential detrimental impacts of those barriers.

2. Focus your paediatric nursing on relationship-building, and be committed to the child or young person and their family needs and
wants. Use a communication style that respects the rights of the child and the family, building their trust as partners in health care and not simply recipients of your service.

3 Be mindful of, and assess, the expressed needs and wants of the child or young person and their family (if possible) before engaging in mental health support. This engages the child or young person and helps build a positive sense of self. Empower children and young people to feel that they are participating fully in the process and the decision-making, both initially and throughout the care. For example, seek the child or young person’s ideas on strategies to implement.

4 Gather information about the child or young person directly from them equally with other sources. Ask what the issue is and why they may be acting the way they are in response. For example, on referral ask the child why they think they are with you and what they would like to achieve. Be collaborative in all care.

5 Focus on outcomes of care, such as developing behaviours that are known to be protective and build resilience. For example, assist the child or young person to identify existing support networks within their life, and encourage aspiration-building and community engagement.

6 Identify and meet immediate needs such as practical support, safety and access to other services. Be practical in the provision of support by providing concrete acts in response to real needs. For example, provision of school breakfast programs can support both learning and behaviour, leading to building self-esteem and resilience characteristics.
7 Have multiple gateways into the support service, and be inclusive by reducing eligibility criteria. Universality of service avoids stigmatisation of mental health service. Ensure a quick response to initial referrals and inquiries for service, and follow up on any absence multiple times. Such actions help build trust.

8 Research has identified protective factors, stresses and circumstances that are strongly predictive of outcomes for children and young people. Many of these factors are malleable, especially when identified early. Paediatric nurses are in a position to identify and intervene to promote positive outcomes for children and young people. Families are especially open to change and support when in contact with paediatric nurses implementing family-focused nursing and family partnerships.

9 Multicultural services are a great starting point; however, they are often unable to adequately meet the specific and complex mental health needs of refugee children and youth. For example, specialist programs and counselling for young people who have experienced torture and trauma should be specifically developed for the needs of young refugees, and bicultural and bilingual services should be available through referral. Promoting the mental wellbeing of newly arrived refugees in schools starts with peer-mentoring programs linking young people with others from similar cultural backgrounds and past experiences.

10 Child and adolescent mental health problems are recognised as an indicator that the child/family is in possible need of targeted support to prevent or address child abuse and neglect. The best way to promote mental wellbeing and protect at-risk children is to prevent child abuse and neglect from occurring through providing assistance
before family problems escalate into crises. Identification of needs and early referral can be achieved through adopting the Common Approach to Assessment, Referral and Support – a short checklist completed in the presence of the child and/or family to identify their needs (see earlier discussion of the Common Approach).

These 10 practical strategies have been collated from ARACY evidence-based reports (ARACY, 2006, 2007, 2010; Fox et al. 2015) and supported with examples from Julia Taylor’s nursing experience.

### Case study 7.5

**Resolution**

You plan to gain further insight into Jason’s mental health by asking whether there have been any changes in his sleeping patterns, appetite, concentration or ability to enjoy and maintain his usual activities. You ask Jason what helps him to cope with stress, school or study problems. During a post-discharge paediatric clinic visit, Jason states that he is feeling happier and that the bullying has lessened. His relationship with his mother is improving. You ask Jason whether he has adult support other than his mum, and Jason states that he is close to his aunt and that she is aware he has been bullied at school. You encourage Jason to talk to her if he needs to do so. You ask Jason whether he feels he is at risk of self-harm, and he says he would never hurt himself. You give Jason the number for Kids Helpline and encourage him to call it at any time if he needs someone to talk to. You later hear that Jason and a newly formed local dance group are to perform at an upcoming community event, which you are looking forward to
attending. This case study raises numerous issues and potential paediatric nursing intervention. Outcomes may vary and new stressors arise for Jason. Many other nursing interventions and strategies beneficial to promoting positive outcomes are not discussed. Can you identify what other essential paediatric nursing care you could instigate and why?

Summary

- Being loved and safe; having strong relationships, positive experiences and supportive environments; actively participating in community and social activities; and fostering a positive sense of culture and identity all help build adaptive capacity in children and young people.

- Building an adaptive capacity allows the child or young person to manage the transitions and stresses they will experience in childhood and throughout life. This is the foundation of mental health, and a resource for recovery from mental illness.

- Mental health can be promoted most effectively using a strengths-based approach, enhancing resilience in children, young people and families.

- All nursing interactions have the potential to build on the determinants of mental health.

Learning activity
Watch the video *Serve & Return: Center on the Developing Child*, Harvard University 2011, *Serve & Return Interaction Shapes Brain Circuitry*, [www.youtube.com/watch?v=m_5u8-QSh6A&list=PL0DB506DEF92B6347](http://www.youtube.com/watch?v=m_5u8-QSh6A&list=PL0DB506DEF92B6347).

Consider how the ‘serve and return’ process can be strengthened in your local area through paediatric nursing practice. By enhancing early child development through paediatric nursing practice, you can strengthen child and youth mental health.

**Further reading**


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**Child and youth mental health** – A state of mental wellbeing in which children and young people can realise their abilities and reach optimal growth and development

**Child and youth mental disorder** – A mental disorder, as distinct from a mental health problem, is characterised by a clinically recognisable set of symptoms or behaviours that interfere substantially with social, academic or occupational functioning. Different types of mental disorders consist of a different combination of symptoms that may differ in severity.

**Child and youth mental health services** – Provide specialist mental health services for children and young people, and assistance to their families or carers

**Risks** – Disturbances to mental health that threaten system function, viability or development

**Resilience** The capacity of a dynamic system (such as a child or family) to adapt successfully to disturbances that threaten system function, viability or development
Evidence-based nursing assessments and interventions: The acutely ill child

Nicola Brown and Robyn Galway

Learning objectives

In this chapter you will:

- Develop your understanding of the evidence-based nursing assessments and interventions used in the care of acutely ill infants and young children
- Develop your understanding of the aetiology, signs and symptoms of key acute illnesses experienced by infants and young children in Australia
- Consider the developmental needs of infants and young children in the planning and implementation of nursing care
- Explore the impact of illness and hospitalisation on infants and young children
Introduction

Children contract infections regularly during early childhood, and are also at risk of injury; thus they can experience episodes of acute illness. For the most part, these episodes are of short duration and resolve with the care of parents at home, sometimes with support from community health care professionals such as a general practitioner. However, in some instances the illness can reach a level of severity that requires nursing care and medical treatment in a hospital setting. Children aged 0–4 years are the most common age group presenting for care in an emergency department (AIHW, 2015). Infants and children are still developing, so they have physiological and anatomical differences from adults that require specialist skills and knowledge. Hospital environments can be challenging for both the young child and their family. For many families, visiting the emergency department with their sick child may be the first time they have ever had to seek acute care from a hospital. It is important that nurses understand this, and that we ensure the child’s care is delivered in a way that is supportive and respectful of the individual child and their family.

In Chapter 6, you were introduced to primary assessment of infants and children and recognition of the sick or deteriorating child. In this chapter, some key nursing considerations and interventions for the acutely unwell child will be discussed. Following this, you will explore some of the illnesses children can acquire that may require hospital care. You will be asked to reflect upon the nursing management of some of these conditions through review of case studies and reflective questions.
Key nursing considerations for the acutely unwell child

**Fever**

Fever is a common and normal response to infection; however, the mechanisms by which fever occurs are still not fully understood (Meremikwu & Oyo-Ita, 2009a). What is known is that infection by organisms such as viruses or bacteria can stimulate release of pyrogenic cytokines that stimulate the pre-optic area of the hypothalamus via humeral and neural pathways to raise body temperature to a higher level than normal (Ogoina, 2011). At a higher body temperature, it seems that the environment for replication of bacteria and viruses can become unfavourable and that immunological factors in the blood, such as white blood cells, may be enhanced (Ogoina, 2011). The fact that fever may be a normal and potentially beneficial response to invasion by pathogens has influenced current practice in the care of children with fever.

Key issues in the monitoring and management of fever in children include definitions of normal body temperature and fever. It is generally accepted that the mean range of normal body temperature is 36.5–37.5°C (Forbes, 2013); however, there is some variation in temperature between individuals and the site of measurement. For example, temperature measurements via the axilla site will be cooler than temperature measurements made via more central sites such as the mouth or tympanic membrane. The variations in range between sites can present an issue when monitoring a trend in temperature over time. It is essential that the site of measurement and the thermometry equipment used are consistent in order to ensure an accurate monitoring of temperature.

The level at which a temperature in an infant or child is defined as a mild, moderate or high fever is less clear. This is complicated by the fact
that infants and younger children have more frequent fevers that tend to be higher, last longer and have more rapid temperature increases (Ogoina, 2011). If you read several textbooks, it is likely that you will find considerable variety in the ranges for fever.

The management of fever has not always been based on the best available evidence. The decision to tolerate or treat fever in children traditionally has been controversial. Fever can contribute to the discomfort of illness for children, and can cause anxiety for parents (Walsh, Edwards & Fraser, 2008); as a result, health-care professionals and parents can feel the need to intervene. However, traditional methods of intervening to reduce fever may not be appropriate. Non-pharmacological methods to reduce fever, such as tepid sponging or fans, are not recommended (Meremikwu & Oyo-Ita, 2009b; Watts & Robertson, 2012). If intervention is warranted, then anti-pyretic medication may be required.

**Anti-pyretic medications**

**Anti-pyretic medications** are generally considered ‘safe’ medications, and are widely available without prescription. The use of anti-pyretic medications such as paracetamol or ibuprofen to reduce fever (Crook, 2010) is not entirely without risk (Meremikwu & Oyo-Ita, 2009b; van den Anker, 2013), particularly when the dosage recommendation is exceeded. For example, overdosing on paracetamol can cause liver damage and overdosing on ibuprofen can lead to renal dysfunction. The action of anti-pyretic medications is not fully understood, but it is postulated that these medications work by reducing the ‘set point’ of the hypothalamic control of body temperature (Rang, Dale & Ritter, 2011). Generally, aspirin should not be used in children due to concerns about the relationship between the use of aspirin and either influenza or varicella, and the

**Reflection points 8.1**

- Even mild episodes of acute illness and fever can make us feel discomfort from pain such as headaches or myalgia.
- In some cases where children are miserable but without a fever, or with only a mild fever, it can be more appropriate to give a medication such as paracetamol for its analgesic properties and the relief of pain and discomfort than to use it as an anti-pyretic.

**Administering oral medications**

For infants and children, the dose of medication prescribed is usually calculated based on weight. In some instances, body surface area (BSA) may be used to calculate medications.

In addition to the usual precautions taken in administering medications to anyone (right medication, right dose, right route, right time, right person), consideration needs to be given to the age and the development of the child. For example, infants are not able to swallow tablets, so wherever possible a liquid preparation of the oral medication would be preferred. The smaller size of children and the variation in size across age groups means that health professionals need to calculate doses and check prescribed doses of medication carefully. Other challenges in administering medication to children include identifying children who are pre-verbal. It is important that the identity of the child is confirmed, either
by the parent or medical identification bracelet, prior to the administration of medications.

Not all oral medications may be available in liquid form. For advice on preparing solid oral medications for administration to infants or younger children, seek advice from a reputable medication information source such as the Children’s Dosing Companion from the *Australian Medicines Handbook* (2017) or a pharmacist.

Administering oral medications to children can be challenging, especially if the child does not want to take the medication or the taste is unpleasant. Some children may be better with a medication spoon, but you may be more comfortable using a syringe – particularly when the child is younger or less cooperative. Wherever possible, nurses should try to make the experience positive.

For practical and comfort reasons, it is wise to sit the child in your lap for administration. It can help to tuck their arm closest to you behind your back and hold the other arm still. Gently administer the oral medication liquid into the mouth, along the inside of the cheek. Administer small amounts, allowing the child to swallow. If you try to administer too much at once, the child may spit it out. Encourage the child to swallow the medication, and give a lot of positive feedback once the process is complete – even if it was a struggle!

Dehydration

Dehydration is a common reason for children to require admission to hospital, and a frequent symptom in children presenting to general practice clinics and emergency departments. While children may become dehydrated for a range of reasons, the most common condition causing
dehydration is acute gastroenteritis. Dehydration from acute gastroenteritis is one of the leading causes of mortality for children in developing countries (WHO & UNICEF, 2013).

**Assessment of dehydration**

Under-estimating the degree of dehydration and not replacing lost fluids and electrolytes can result in acidosis, electrolyte imbalance, renal damage or death. Initial and ongoing assessment of dehydration is a crucial step in determining required treatment and need for hospitalisation.

Several scales and algorithms have been developed to assess and treat dehydration. Commonly used assessment scales include the World Health Organization’s (WHO) Scale, the Gorelick Scale and the Clinical Dehydration Scale (CDS) (Pringle et al., 2011). Each scale predicts percentage of estimated weight loss due to fluid loss for different age groups. For example, the WHO and Gorelick Scales are used in children aged from 1 month to 5 years, and the CDS is used in children aged from 1 month to 3 years. Each scale assesses a range of clinical signs associated with dehydration. In Australia, some modifications of these scales have been developed by expert groups (see Table 8.1).

**Table 8.1** Commonly used scales for assessment of dehydration

<table>
<thead>
<tr>
<th></th>
<th>WHO</th>
<th>CDS</th>
<th>Gorelick</th>
<th>NSW Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group Signs</td>
<td>1 month–5 years</td>
<td>1 month–3 years</td>
<td>1 month–5 years</td>
<td>Not stated</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Condition/level of consciousness</th>
<th>General appearance</th>
<th>General appearance</th>
<th>Lethargy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyes (normal or sunken)</td>
<td>Eyes</td>
<td>Capillary refill</td>
<td>Capillary refill</td>
</tr>
<tr>
<td>Thirst</td>
<td>Mucous membranes</td>
<td>Tears</td>
<td>Mucous membranes</td>
</tr>
<tr>
<td>Skin pinch</td>
<td>Tears</td>
<td>Mucous membranes</td>
<td>Eyes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyes</td>
<td></td>
<td>Breathing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathing</td>
<td></td>
<td>Quality of pulses</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of pulses</td>
<td></td>
<td>Skin turgor</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin elasticity</td>
<td></td>
<td>Heart rate</td>
<td></td>
</tr>
</tbody>
</table>
Essentially, the differences between mild, moderate and severe dehydration are based on changes in the signs of circulation – especially colour, heart rate, activity level, peripheral perfusion, urine output and blood pressure. Early signs of mild dehydration, such as pallor, dry mucous membranes and diminished urine output, are the result of compensatory mechanisms in response to decreased fluid volume. As dehydration becomes moderate, and then severe, signs that the circulation is compromised become more apparent. Signs of moderate to severe dehydration include worsening colour, deterioration in level of consciousness, increasing tachycardia, decreased capillary refill, deterioration in skin turgor and lastly hypotension. Hypotension in infants and children is considered an ominous sign of severe dehydration, indicative of hypovolaemic shock.

**Intravenous therapy**

Restoration or maintenance of normal fluid and electrolyte balance is an essential component of care of the sick infant or child. For many reasons, infants or children may be unable to maintain a normal intake of fluids because they are sick or because they are being kept nil by mouth. Children with acute illness frequently require intravenous access for a range of reasons, including the administration of fluids, medication, blood
products and/or blood sampling. Most often, intravenous access for short-term use is obtained via peripheral venous cannulation. Obtaining and maintaining intravenous access in infants and children can be challenging for many reasons, including the smaller relative size of children’s blood vessels and the fear, anxiety and pain caused by the procedure.

Generally, the site of intravenous cannulation is determined on the basis of the child’s history and the type of medication or fluid that is to be administered (Rathnayake, 2012). In most instances, the first site of choice will be the dorsal aspect of the child’s non-dominant hand. Other sites that may be considered are the wrist, leg, foot and scalp.

Topical anaesthetics (such as EMLA or amethiocaine) can be applied prior to cannulation to the site(s) of choice to reduce the pain associated with venipuncture, but these generally need to be applied 45 minutes to one hour before cannulation is attempted. Although there is good evidence that topical anaesthesia reduces the pain associated with venipuncture and cannulation (Rathnayake, 2012), some clinicians may elect not to use it as it may cause transient vasoconstriction of superficial vessels. However, results from the first prospective study to compare the success rate of cannulation with or without EMLA found no significant difference in success rate (Schreiber et al., 2013). While these results suggest that EMLA may not reduce the success of cannulation, further studies are required to confirm these findings and reduce clinicians’ concerns.

Preparing the child and family for intravenous cannulation

Depending on the age of the child, their capacity to cooperate during cannulation may be limited by their development and their feelings of fear and anxiety. It is important that these factors are taken into consideration when preparing the child and family. In the first instance, parental consent
will need to be obtained for the procedure, and details of the approach to
the procedure discussed initially with the parent, and then with the child
using developmentally appropriate language. It may be necessary to hold
the child or their limb during the procedure, and parents should be given a
choice about their role in this. At a minimum, children will need their
parent close by to provide comfort after the procedure. Partial wrapping of
the child’s body, leaving the limb intended for cannulation free, can help
the parent to hold the child more easily during the procedure.

In addition to topical anaesthetics to reduce the pain of cannulation
mentioned earlier, we should consider the use of distraction and other
methods to reduce pain. For infants, parent presence, physical comfort and
non-nutritive sucking with sucrose or a dummy are simple interventions
that may provide comfort during the pain of cannulation. For children,
looking at books, blowing bubbles, watching a movie or listening to music
are some techniques that can be used.

**Monitoring the intravenous site and infusion**

Intravenous cannulation is painful and distressing for children, and may be
technically difficult for clinicians, so protection of a patent cannula is
essential. It is important that the child’s developmental stage, the condition
of their skin, the location of the site and the child’s mobility are taken into
consideration. The cannula is normally secured at the insertion site with
sterile opaque dressing or tape, so that the site can be visualised and
monitored for inflammation, leaking and infiltration. Depending on the
position of the site and the mobility of the limb, it may be necessary to
splint the limb to ensure patency of the cannula. Accessing the intravenous
line should be performed using an aseptic non-touch technique (NHMRC,
2010). The site should be checked frequently – up to hourly as required.
An intravenous infusion pump is used to ensure the accurate rate of fluids is infused. Administration of intravenous fluids should be recorded accurately in the child’s fluid balance chart in addition to other fluid intake and output.

Extravasation occurs when fluids leak unintentionally from the cannulated blood vessel into surrounding tissues. This may occur due to dislodgment of the cannula from the vessel, or occlusion. The incidence of extravasation may be higher in children due to factors such as smaller, fragile vessels and the risk of child interference with the cannula. Even though the flow rates of fluid may be comparatively smaller in children, their smaller body mass means that the swelling associated with extravasation may cause a significant injury to the tissues if not recognised early. It is essential that when extravasation is suspected, the infusion should be stopped and the site of extravasation assessed to determine the severity of the injury. Awareness of the risk and management of extravasation is an important part of the skill of caring for a patient with an intravenous infusion.

**Intravenous fluids: Types and volumes**

Infants have higher total body water than older children and adults, and turn over their body water more frequently. In addition, infants have a higher body surface area:mass ratio, and are therefore more susceptible to insensible fluid losses. As a result, accurate and careful calculation of fluid volumes is required. Infants and children are generally prescribed fluids based on body weight. Sometimes their fluids may be calculated based on body surface area. There are different methods for calculating fluid requirements, based either on total daily amounts or hourly amounts.
In addition to different fluid volumes, the types of intravenous fluids used in children are slightly different from those used for adults. Intravenous fluids used for maintaining hydration generally contain a mixture of sodium chloride and glucose. Younger infants have higher energy needs, so they may be prescribed a higher concentration of glucose than older infants and children. For intravenous rehydration fluids, generally 0.9 per cent sodium chloride with 5 per cent glucose is the fluid of choice (New South Wales Health, 2015).

**Oxygen therapy**

Oxygen therapy is an important intervention utilised to correct or prevent hypoxia in children with acute illness or injury. Oxygen may be administered via a range of devices, including a face mask and nasal prongs. The flow rate and concentration of oxygen administered will vary according to the device, and are also influenced by the flow rate of the oxygen through the device, patient needs and health goals, the respiratory rate and the tidal volume of the infant or child (Balfour-Lynn et al., 2009; Sim et al., 2008). Table 8.2 provides some considerations necessary when choosing an oxygen delivery device.

**Table 8.2 Summary of oxygen-delivery systems**

<table>
<thead>
<tr>
<th>System</th>
<th>Percentage of oxygen delivered</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nasal prongs</td>
<td>Maximum rate 4 L/min 25–40%</td>
<td>For children with mild or moderate respiratory distress. May be irritating.</td>
</tr>
</tbody>
</table>
### Nasal prongs

Delivery of oxygen via nasal prongs is a frequently used technique in infants and younger children with signs of mild to moderate respiratory symptoms (1–4 L/minute) (Torrey, 2015) and for children requiring longer-term oxygen therapy, both in hospital and the community (Balfour-Lynn et al., 2009). For children with significant respiratory distress, such as with the respiratory illness bronchiolitis, higher-flow oxygen can be delivered via specifically designed nasal prongs, which can safely deliver higher rates of up to 8-25 L/min (Lee et al., 2013). When oxygen is

<table>
<thead>
<tr>
<th>Method</th>
<th>Flow Rate</th>
<th>Oxygen Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>High-flow humidified nasal prongs</td>
<td>1–2 L/kg/min</td>
<td>For severe respiratory distress</td>
</tr>
<tr>
<td>Face mask</td>
<td>4 L-8 L/L/min 35%–50%</td>
<td>Percentage of oxygen received affected by the fit of the mask</td>
</tr>
<tr>
<td>Non-rebreather face mask</td>
<td>8 L-15 L/min 80–100%</td>
<td>Inflate bag before placing on child. Bag must remain two-thirds inflated for duration of treatment</td>
</tr>
</tbody>
</table>
delivered at flow rates higher than 2 L/minute or for extended periods, nares can become dry and irritated, causing damage to the mucosa and cilia. Humidification and warming of the oxygen at these higher rates is necessary; this prevents these issues and promotes gas exchange (Dysart et al., 2009).

Nasal prongs are helpful when children do not tolerate a face mask and they also allow continuation of feeding without interruption of oxygen delivery. Due to the risk of drying and irritation to the mucous membranes, the nares need to be inspected regularly and care taken to protect the skin. Nasal prongs may also be a strangulation risk to infants and children, and therefore the tubing should be carefully secured on the face and checked regularly.

### Face mask

Face mask oxygen is useful where higher flow rates of oxygen are required in spontaneously breathing patients. A face mask fits over the mouth and nose, which increases the oxygen reservoir, thus in turn increasing the amount of oxygen that can be delivered. The level of oxygen varies, but rarely exceeds 50 per cent (Torrey, 2015) and depends on the flow rate of the oxygen and the volume of room air that is drawn in around the face mask during inspiration. A minimum of 4 L/minute of oxygen is required to avoid build-up of carbon dioxide. Rebreathing of carbon dioxide will cause drowsiness.

When a child requires higher concentrations of oxygen, a further method of delivery is via a partial or non-rebreathing face mask. This mask again fits over the mouth and nose, and has an additional oxygen reservoir bag that has a valve system in place to prevent exhaled gases from mixing with fresh gas flow. The non-rebreathing mask system may
also have a valve on the side ports of the mask that prevents room air from entering into the mask. The amount of oxygen that can be provided is greater than 60 per cent; this is the highest delivery method for a patient who is breathing spontaneously (Torrey, 2015).

Remember these important nursing considerations:

- The child requiring oxygen needs close observation, no matter which device is in place. Observations that must be attended to include work of breathing, heart rate, respiratory rate and response to treatment, and these should be performed and recorded at least once per hour.

- Check that oxygen is being delivered at the prescribed rate. The flow meter must be checked with each patient assessment.

- Check that the appropriate size of device is being used for the age and size of the child.

- Each institution will have specific guidelines for the management of oxygen therapy; these must be adhered to all times.

(Adapted from Lee et al., 2013 & Joanna Briggs Institute, 2016)

**Pain assessment**

Pain is a common symptom of many childhood illnesses, so assessment of pain is a nursing priority. Assessment of pain in children can be challenging.

Pain is only truly able to be expressed by the person experiencing it, and therefore self-reporting is the most accurate assessment. When caring for children, self-report may not be possible due to factors including
language levels, previous experiences and cognitive development. The nurse can utilise changes in physiological parameters – for example, a rise in heart rate or changes in respiratory rates and patterns; however, these are not always reliable (Brummelte, Oberlander & Craig, 2014), as they may also be signs of the underlying illness. Furthermore, some children may deny pain if they have concerns that intervention by health-care professionals may worsen pain or lead to procedures (such as cannulation) that may result in further pain. The three main approaches to the assessment of pain in children include self-reporting of pain by children or their parent/s, observation of behaviours, and physiological signs that are known to reflect pain (APAGBI, 2012).

No single pain-assessment tool can be recommended for use in all children. Recent evidence-based practice guidelines for pain management have made recommendations for the use of behavioural and self-report tools in the assessment of pain in children (see Table 8.3).

**Table 8.3** Recommended measures for the procedural and postoperative pain assessment based on chronological age with no cognitive impairment

<table>
<thead>
<tr>
<th>Child’s Age</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn–3 years</td>
<td>COMFORT or Face Legs Arms Cry Consolability (FLACC) Scale</td>
</tr>
<tr>
<td>4 years</td>
<td>Revised Faces Pain Scale + COMFORT or FLACC</td>
</tr>
<tr>
<td>5–7 years</td>
<td>Revised Faces Pain Scale</td>
</tr>
</tbody>
</table>
Observational and behavioural pain-assessment tools

The signs and symptoms of pain can be similar to fear or distress, and at times it can be difficult for the practitioner to determine which of these they are observing. This can be particularly challenging in infants and younger, pre-verbal children. For these groups of children, observational and behavioural tools are used for pain assessment. Currently, the COMFORT and Face Legs Arms Cry Consolability (FLACC) scales are most commonly recommended for use as observational and behavioural pain-assessment tools.

The COMFORT behaviour scale was initially developed to assess distress in infants in the paediatric intensive-care setting (Ambuel et al., 1992), but has since been validated for the assessment of pain intensity and distress in other age groups, including ventilated adults in intensive care settings (Ashkenazy & DeKeyser-Ganz, 2011) and older infants and toddlers (van Dijk et al., 2000). The scale is based on behavioural and physiological signs. Scores are given for alertness, calmness, respiratory distress, crying, physical movement, muscle tone, facial tension, mean arterial pressure and heart rate.

The FLACC scale is used to quantify pain behaviours in children. It was first developed for assessing post-operative pain in infants and children aged under 7 years (Merkel et al., 1997), and it has since been validated in other studies with similar-aged children (Manworren & Hynan, 2003; Willis et al., 2003), older children and adolescents (Nilsson,
Finnstrom & Kokinsky, 2008), children with cognitive impairment (Malviya et al., 2006) and in one study of non-Western children (Bai et al., 2012). The FLACC scale requires the health-care practitioner to assess the degree of tension evident in the face and legs, the level of activity, the extent of crying and how easily the infant or child can be consoled.

To assist in the pain assessment of children with cognitive impairment, the revised FLACC scale (r-FLACC) can be utilised.

**Self-report tools**

Self-report tools are commonly used in children over the age of 5 years, who are able to provide a verbal self-report of pain. While many self-report tools have been developed as a way to measure children’s self-reporting of pain, not all are used effectively or consistently, or they lack repeated evaluation data. The self-report tools most commonly evaluated, used and recommended are the Faces Pain Scale – Revised (FPS–R), visual analogue scales (VAS) and numerical rating scores (NRS).

**Pain management**

There are many different reasons why a child may experience pain. The pain maybe acute, chronic or related to a procedure. Whatever the source of the pain, it is vital that pain is managed adequately so ongoing negative physiological and psychological impacts are minimised. Examples of these negative outcomes are changes in vital signs, fear, anxiety and developmental regression (Woragidpoonpol et al., 2013; Koller & Goldman, 2012). Pain management, like pain assessment will be individualized. The type and source of the pain will assist in determining
the management and can be a mix of non-pharmacological and pharmacological methods.

Non-pharmacological pain management has been comprehensively researched and can be used as an effective standalone measure or as an adjunct to pharmacological treatment (Woragidpoonpol et al., 2013; Wente, 2012; Koller & Goldman, 2012; Pillai Riddell et al., 2015; Srouji, Ratnaplan & Schneeweiss, 2010). Nurses are able to institute many common non-pharmacological measures, which can be as simple as swaddling, administration of sucrose prior to procedures, singing, holding and simple distraction with toys, games, or books. Other more complex measures, such as guided imagery, breathing exercises, positive reinforcement, and comfort positioning, can be implemented with the assistance of colleagues trained in these procedures.

Simple analgesics such as paracetamol and ibuprofen are frequently used as first-line pharmacological pain management for mild to moderate pain such as earache (otalgia) through to acute post-operative pain (Penrose, Palozzi & Dowden, 2013). These medications may be used under medical supervision in combination with each other or with opioids when pain is more severe (Bearde & Greco, 2011). Opioids such as morphine are recognised as safe and effective analgesics, and are available in many different preparations to enable effective delivery. Whether they are administered orally, rectally, via inhalation or intravenously, all children require close monitoring for side-effects such as sedation, respiratory depression, urinary retention, pruritus, and nausea and vomiting (Penrose, Palozzi & Dowden, 2013).

Regional anaesthesia, which is the administration of local anaesthetic, is also an effective method to address acute pain. This method is often used post surgery either into the epidural space for pain relief below the
waist or peripherally into a nerve plexus and provides complete blockage of pain transmission.

All methods of pain management have protocols to ensure safe and effective care. Health-care facilities will specific nursing guidelines to adhere to. Before providing nursing care to children with complex pain management in place, it is the responsibility of each nurse to familiarise themselves with the pharmacokinetics and side-effects of all analgesic medications.

**Reflection points 8.2**

- There are many validated pain-assessment tools available in various texts and clinical guidelines. Take time now to find a few, such as FLACC, FPS-R or VAS and think about how they might be used when caring for a child with acute pain. For example, the FLACC scale is available on the Paediatric Nursing in Australia: Principles for Practice companion website at [www.cambridge.edu.au/academic/paediatrics2e](http://www.cambridge.edu.au/academic/paediatrics2e).

- Topical analgesia has been discussed in this chapter as an example of assisting in a painful procedure – cannulation. Take time to review this section again and reflect upon other combinations of pharmacological and non-pharmacological methods that you might use when caring for a child with pain.

- One of the more challenging aspects of caring for children can be communicating our intentions to perform procedures that may cause fear, anxiety or pain. When we plan to talk to children about a procedure like intravenous cannulation, there are a number of issues to take into consideration:
Common acute illnesses in childhood

Most children will experience short-term acute illnesses during childhood that resolve without the need for admission to hospital. However, for some the extent of the illness may be of sufficient severity to require admission to hospital. While it is beyond the scope of this chapter to cover all the illnesses that may require acute nursing and medical care in hospital, we will briefly explore some common conditions, including their likely causes, signs and symptoms.

In the previous section, we discussed key interventions for children with acute illness, including management of fever, dehydration and oxygenation. This section presents case studies of children with common illnesses. Take some time to consider how the assessments and interventions we have previously explored in Chapter 6 and this chapter may be used for children with the illnesses outlined below.

Case study 8.1

Discuss the implications of each of these when undertaking a procedure on a child.

- their stage of cognitive development
- their understanding of language – for example, whether their primary language is the same as ours
- the presence of parents
- the timing of the information
- prior experiences of painful or distressing procedures.
Ying

Ying is an 18-month-old girl brought to the emergency department by her mother and father. Ying’s mother explains that Ying has been vomiting sporadically for 12 hours, and experienced a brief seizure at home. She is not sure how long the seizure lasted for, but thinks it was less than a minute. Ying’s father explains that during the seizure, Ying was staring, had rhythmic clenching of both fists and her body and limbs were rigid.

Ying is pale, sleepy and lethargic. She feels peripherally warm to touch. Her heart rate is 165/min, respiratory rate is 35/min, blood pressure 95/60 and temperature 39.0ºC. Her mouth and lips are dry. Her parents report that she has not kept down any fluids for 12 hours. Each time Ying drinks fluids, she vomits, and she has only passed urine once since the vomiting began.

Febrile seizures

Some children will experience a single, brief febrile seizure before the age of 5 years (Reid et al., 2009). Typically, it will be a generalised tonic-clonic seizure, lasting only a minute or two. In most instances, the seizure is caused by a sudden rise in core body temperature. In infancy and early childhood, children are more susceptible to such seizure triggers, as the cerebral cortex is quite excitable, and consequently the threshold for a seizure is lower (Lux, 2010). However, in a few cases, repeated or longer seizures may indicate a more serious condition, such as meningitis or epilepsy (Lux, 2010). If an infant or child has a seizure, it is considered a medical emergency in the first instance.

Studies into the use of prophylactic treatment of febrile seizures do not support the use of anti-epileptic medications or anti-pyretic
medications to prevent a fever (Offringa & Newton, 2012), particularly as some of the anti-epileptic medications have undesirable side-effects. More importantly, parents should be advised on the first aid response to a seizure, the risk of recurrence and when to seek medical advice.

For most parents, their child’s febrile seizure is their first experience ever of a seizure, and can be a frightening experience. It is important that health professionals are sensitive to the distress that parents have experienced, even though the relative risk associated with a simple febrile seizure may be mild.

**Acute respiratory illness**

**Case study 8.2**

**Jayden**
Jayden is a 2-year-old boy brought to the emergency department in the late evening by his mother. Jayden’s mother explains that he has had a barking cough during the day that has become progressively worse. She is concerned that he seems to be working harder to breathe, even when asleep.

Jayden is pale and sleeping in his mother’s arms. As Jayden takes a breath, there is a loud stridor on inspiration and a softer noise on expiration. You notice that Jayden has tracheal tug on inspiration, and noticeable use of abdominal muscles during respiration. After a few minutes, Jayden rouses and coughs loudly before falling back to sleep.
Acute respiratory illnesses that are characterised by some degree of upper or lower airway obstruction are among the most common reasons why children in Australia require nursing care and hospitalisation (AIHW, 2015). Essentially, the younger a child is, the narrower their airways are, and thus the more likely they are to develop airway obstruction as a result of the inflammation. The extent to which infants and children become unwell with respiratory illness can vary considerably between individuals and, depending on the cause and site of the obstruction, sick infants and children can further deteriorate in a relatively short timeframe, as outlined in Chapter 6.

**Respiratory tract infections**

Respiratory tract infections caused by viruses are a very common event in the lives of children. In most instances, children have a mild illness that resolves within a few days, and some children will develop a severe infection that requires admission to hospital. Symptoms vary, depending on the site and cause of the infection, but in general children are more likely than adults to have symptoms of fever, discomfort and decreased fluid intake.

**Croup**

Croup (laryngotracheo-bronchitis) is the most common obstructive disorder of the upper airway, usually caused by viruses such as Para influenza types 1 and 2 (Schomacker et al., 2012; Woods, 2015). The signs of croup are characteristic – an inspiratory stridor, barking cough and onset in the evening and at night. In mild cases, these symptoms resolve within a few days. Nonetheless, the symptoms of croup can be frightening for the child and parent.
Croup is usually mild in children, and can be cared for at home, usually after review by a general practitioner. Children with moderate or severe croup require review and close monitoring by health professionals in an emergency department, and may require admission. However, the early use of oral corticosteroids, which can quickly reduce the inflammation in the upper airways and thus reduce obstruction, have significantly reduced both the need to be admitted and the time required for admission in hospital (Dobrovoljac & Geelhoed, 2012).

Any child with stridor requires close and careful monitoring and assessment, as it can worsen and lead to severe airway obstruction. Furthermore, stridor with drooling and without coughing may indicate the presence of epiglottitis or bacterial tracheitis (Paul, O’Callaghan & McKee, 2011; Tibballs & Watson, 2011), conditions associated with acute airway obstruction that require intubation and intensive care.

It is essential to establish the extent of airway obstruction, as this is the main criterion for determining the degree of severity of illness in a child with croup; for this reason, very careful respiratory assessment is required (see Chapter 6). Children with croup are generally considered to have mild croup when they are interacting normally with parents and their environment. These children may have an audible inspiratory stridor when they are active, but the stridor is absent at rest. When stridor is present even at rest, then children are considered to have moderate croup. More severe croup is characterised by worsening airway obstruction, causing anxiety, sleepiness, marked tachycardia and pallor. Severe airway obstruction is an emergency, and intubation may need to be considered (Woods, 2015; Zoorob, Sidani & Murray, 2011).

Children with mild croup require close parental supervision and care at home. Historically, parents have often been advised to reduce stridor by exposing their child to a warm, humidified environment, such as a
bathroom with a warm shower running, or steam inhalations. However, there is little evidence that this is effective, and there are also concerns that the use of steam inhalations increases the risk of burns and scalds (Fitzgerald & Kilham, 2003; Zoorob et al., 2011). It is more important to ensure that parents are aware of, and watching for, the signs of increasing airway obstruction.

Medications are the mainstay of treatment for children with moderate and severe croup. The use of corticosteroids such as oral dexamethasone or nebulised budenoside in the management of croup has significantly reduced the length of time required in hospital for children with croup (New South Wales Health, 2010). Children with moderate and severe croup will generally be prescribed oral or nebulised corticosteroids (Mazza et al., 2008). Some children with mild croup may also be prescribed a single dose of oral corticosteroid (Russell et al., 2011). Nebulised adrenaline may be required to reduce bronchial and tracheal oedema in children with severe croup, and can rapidly reduce the symptoms of croup in 30 minutes (Bjornson et al., 2011). Further doses may be required after two hours.

Discharge from hospital can occur when no stridor is present. At the time of discharge, the parents should be provided with education or a fact sheet and have organised follow-up with a general practitioner (New South Wales Health, 2010).

**Bronchiolitis**

Bronchiolitis is caused by a viral infection of the lower airways in infants. While a number of respiratory viruses can cause the wheezing-like symptoms seen in bronchiolitis, including adenoviruses, rhinoviruses and influenza, the most common cause of severe bronchiolitis is respiratory
syncytial virus (RSV) (Mansbach et al., 2012). Despite a high rate of infection, immunity does not last long, so repeated RSV infections can occur. The signs and symptoms of bronchiolitis include wheezing, difficult feeding, pallor and respiratory distress.

While some infants have mild bronchiolitis, those who have respiratory distress, hypoxia, lethargy or cannot maintain adequate fluid intake due to poor feeding will require admission to hospital. Treatment is essentially supportive, and may include suctioning of the naso-pharynx, respiratory support with oxygen using various delivery devices to prevent hypoxia, intravenous fluids to maintain hydration or nasogastric feeding (Piedra & Stark, 2016). Case Study 6.1 in Chapter 6 discussed the case of Maggie, an infant with bronchiolitis, and outlined the nursing management required.

**Pneumonia**

Pneumonia is a lower respiratory tract infection with presenting signs of cough, increased secretions, pain in the chest (or commonly abdomen in children), fever and respiratory distress (McIntosh, 2002). Pneumonia is a common illness in young children, with the World Health Organization estimating that there are 20 million admissions of children under 5 years of age to hospital each year with this diagnosis, and many more who are treated in the community (Rudan et al., 2008). This illness is more prevalent in lower socioeconomic groups due to overcrowding, and thus ease of transmission of the infective agents. Children who have underlying cardiopulmonary conditions such as asthma, congenital heart disease and immunity disorders have a higher risk of contracting pneumonia.

Treatment of pneumonia is supportive and similar to bronchiolitis, with the addition of intravenous antibiotics. Pneumonia is predominantly
bacterial in origin; however, viral infection is also common. Pneumonia can be prevented with immunisation of the Haemophilus influenza type B (HIB) and pneumococcal conjugate vaccines (Barson, 2015), so opportunistic parental education and immunisation is another important nursing consideration.

**Acute otitis media**

**Case study 8.3**

**Lucas**

Lucas is a 7-month-old infant brought to the after-hours general practice clinic. Lucas's parents report that he has cried inconsolably for six hours and has little interest in breastfeeding or solids. Lucas appears pale and is peripherally warm. He is noticeably irritable, and crying despite being held by his mother. He has profuse nasal secretions and a dry mouth. His parents are concerned that he has not had a wet nappy for six hours. The general practitioner inspects his ears and notes bilateral inflamed tympanic membranes, with a bulging right tympanic membrane. Lucas has a heart rate of 172/minute, a respiratory rate of 44/minute and his axilla temperature is 39.7°C.

Acute otitis media (AOM) refers to an infection or inflammation of the middle ear, characterised by fluid collection in the middle ear and a bulging tympanic membrane. Up to 60 per cent of children aged under 3 years will have at least one episode of otitis media during early childhood (Klein & Pelton, 2015; Wood & Vijayasekaran, 2014), and the incidence is
higher still in Aboriginal and Torres Strait Islander children (AIHW, 2014). Children of this age are more likely to develop ear infections as they have short, horizontal Eustachian tubes that are less likely to drain fluid produced during an upper airway infection. AOM is more likely to occur in households with smokers, where there has been a lack of breastfeeding, in infancy and toddlerhood, in children exposed to more frequent upper respiratory tract infections (URTI) through childcare attendance and in lower socioeconomic status groups (Klein & Pelton, 2015).

The signs of AOM are usually fairly rapid in onset. Most children will present initially with vague or non-specific complaints such as being irritable and difficult to settle, and may have loss of appetite and interest in drinking their usual fluids. More definitive signs include fever, earache (or rubbing of the ear in pre-verbal children) and sometimes discharge from the ear if the tympanic membrane ruptures. Many children will have had a recent history of an URTI, including a sore throat and rhinitis. A diagnosis of AOM is made based on these clinical signs with confirmation of a bulging and reddened tympanic membrane. The tympanic membrane is visualised using an otoscope. Normally, a tympanic membrane is a pale pearl-pink colour. In AOM, the membrane is redder and may bulge from the build-up of fluid in the middle ear.

**Reflection point 8.3**

An earache can be very painful and distressing for an infant or child. Take some time now to review the methods of pain assessment provided at the beginning of the chapter and consider which tools would be useful for assessing pain in children less than 3 years of age.
Management of pain associated with AOM is an important intervention. Relief from pain can help the child to settle to sleep, and may improve their intake of oral fluids. In most cases, oral analgesics such as paracetamol or ibuprofen can be used to reduce the pain. Although the main purpose of using either paracetamol or ibuprofen is to reduce pain in this circumstance, these medications can also reduce any fever that is present.

Pain and fluid management are the primary considerations for managing AOM, with most incidences resolving over a period ranging from two days to two weeks. Concerns about the over-use of oral antibiotics in the community have led to the development of evidence-based guidelines to encourage more judicious use of antibiotic therapy in the treatment of AOM. To date, evidence suggests that antibiotics are appropriate for the treatment of children under 2 years of age with bilateral AOM or for children with both bilateral AOM and a discharge from the ear (otorrhoea) (Venekamp et al., 2015; Wood & Vijayasekaran, 2014). If pain persists for longer than 48 hours, the child should be reviewed and antibiotic therapy may be then considered. An important consideration with recurrent or undiagnosed episodes of AOM is that this may lead to a chronic collection of fluid. Chronic otitis media may lead to conductive hearing loss, with subsequent delays in cognitive, speech and language development (Monasta et al., 2012; Wood & Vijayasekaran, 2014).

**Gastroenteritis**

Viruses – particularly rotavirus – are the most common causative pathogen of gastroenteritis in children (Kesson, Benwell & Elliott, 2010; NHMRC, 2013). Health-care service demands arising from rotavirus infections alone
in Australia were estimated to be around $30 million (Galati et al., 2006) prior to the addition of the rotavirus vaccine to national immunisation programs. This does not take into consideration the impact of the illness on the community in terms of lost work hours from parents. Since the introduction of the nationally funded rotavirus vaccination program, there has been a significant decline in the rate of hospitalisations for rotavirus infections for children under 5 years of age – an estimated reduction of 7700 hospitalisations per year (Dey et al., 2012).

Viral gastroenteritis causes injury to the small bowel, resulting in low-grade fever and watery diarrhoea (Dalby-Payne & Elliott, 2011). Children can also develop bacterial gastroenteritis, primarily through food poisoning. There is an additional risk that bacterial gastroenteritis can progress to become a more systemic infection, resulting in sepsis and shock (Dalby-Payne & Elliott, 2011).

**Hydration and diet for children with acute gastroenteritis**

Oral rehydration therapy (ORT) using commercially developed modified glucose and sodium solutions is one of the safest and most effective methods of treating mild to moderate dehydration caused by diarrhoea and vomiting (Dalby-Payne & Elliott, 2011). In most instances, ORT is used orally; it is given in small frequent amounts over several hours as a ‘trial of oral fluids’ to see whether increased fluid and electrolyte intake via the oral route can result in rehydration without the need for intravenous cannulation and fluid therapy (Hartling et al., 2006). If vomiting persists or a child refuses to drink ORT, consideration may be given to administering ORT via a nasogastric tube.

For children with moderate to severe dehydration, intravenous fluids may be required. Children with the clinical signs of severe dehydration,
including hypotension, may require fluid resuscitation with fluid boluses to ensure adequate circulation (NIHCE, 2009).

An early return to normal diet and the reintroduction of milk are now encouraged for infants and children with acute gastroenteritis once vomiting has subsided. Breastfeeding can continue through the illness period. Evidence suggests that early resumption of diet is associated with a reduction in number of bowel motions, reduced duration of illness and lower weight loss (NIHCE, 2009). There is growing interest in the use of probiotics, as evidence indicates that they may reduce the duration of diarrhoea and length of stay in hospital (Dalby-Payne & Elliott, 2011).

**Rashes in childhood**

Rashes are common in childhood, and may be caused by a wide variety of agents, including viral and bacterial infection, allergy and autoimmune disease. While the rash itself is often self-limiting, rashes can be associated with serious and life-threatening illness, and thus must be investigated. When investigating the rash, factors such as appearance, preceding and accompanying symptoms, location, exposure to medication and recent travel need to be assessed to determine the significance of the rash (Kang, 2015; Watkins, 2013). Rashes are categorised as infectious or non-infectious, acute or chronic, localised or diffuse, and described by their appearance. No matter what the description may be, a rash that appears when a child has a fever or vomiting needs to be taken very seriously and investigated immediately (Kang, 2015).

**Reflection point 8.4**
Rashes have descriptive terms such as macular, papular, pustule and vesicle. Take the time now to review the meanings of these terms.

**Meningococcal disease**

Meningococcal disease is a serious life-threatening disease that can cause inflammation of the lining of the brain (meningitis) or blood poisoning (septicaemia). Meningococcal disease is infectious and a major worldwide health problem primarily affecting those aged under 5 years. Most children with meningitis will have had a history of preceding upper respiratory tract infection and have symptoms including fever, headache, pallor, photophobia, tachycardia, irritability, nausea and vomiting. In many cases, a later sign is the development of a characteristic petechial rash on the skin and mucosa. Petechiae are small haemorrhagic red or purple spots, generally 1–2 mm in size, which do not blanch when pressure is applied. It is important to remember that there are other causes of petechiae, such as trauma, excessive vomiting or coughing (Paller & Mancini, 2011; CDNA, 2014).

Meningococcal diseases are easily treated with antibiotics; however, early recognition is vital for a positive outcome. If not treated promptly, critical illness or death may occur within 24 hours of symptoms arising. Those who survive can incur permanent physical damage, including deafness, and skin and limb loss (CDNA, 2014).

**Parvovirus (fifth disease)**
Parvovirus is an infectious viral disease affecting preschool and school-aged children. The characteristics of this illness are rhinorrhoea, fever and a rash that starts on the cheeks and after a few days may spread to the arms and legs. The facial rash gives the appearance of a slapped cheek and thus this disease is often called ‘slapped cheek disease’. Parvovirus is generally a self-limiting disease; however, if contracted by a pregnant woman, it may result in a poor outcome for the foetus (CDNA, 2000).

**Atopic dermatitis (eczema)**

Eczema is a common non-infectious, inflammatory disorder that presents initially as a dry and itchy rash. The symptoms often occur on skins folds such as the elbows and knees. Due to the skin being dry and prone to scratching, the skin can break, leaving wounds that exude fluid. Broken wounds can become infected. Treatment is supportive, including topical anti-inflammatory creams and antibiotics for infected wounds.

**Hand, foot and mouth disease**

Hand, foot and mouth disease is a viral illness commonly originating from the coxsackie, echo and entero viruses. This disease generally affects children aged 1–4 years. Children display symptoms of a fever, sore throat, cough and general lethargy, with decreased appetite and a vesicular rash on the palms of the hands and soles of the feet, with some oral vesicles and erosions present. The painful vesicles and erosions generally disappear after seven days; however, during this time parents will need to monitor oral intake and provide regular analgesia (Paller & Mancini, 2011; Treadwell, 2015).
Anaphylaxis

Anaphylaxis is an allergic reaction that causes urticarial symptoms (painful and itchy, pale or red raised lumps) and swelling of the airways, lips and eyes. Along with the skin reaction, the allergy has a multi-organ effect, primarily affecting the respiratory system in children, with wheezing and shortness of breath common features (Dinakar, 2012). The allergy can come from a variety of sources, including shellfish, bee stings, tree nuts and medication. Anaphylaxis is life-threatening, so early recognition and treatment are vital. Treatment is administration of subcutaneous adrenaline and supportive management as oxygen and intravenous fluids (Dinakar, 2012; Treadwell, 2015).

Many diseases that have characteristic rashes, such as mumps, measles, varicella (chickenpox) and rubella are preventable with immunisation, so parental education is an important nursing consideration.

The conditions outlined above are just a very small sample of rashes that bring children to hospital. To further your knowledge of childhood rashes and to familiarise yourself with the appearance of a rash, it is important to undertake further research. At the end of this chapter, there are some websites that may be useful in your initial investigations.

Infantile hypertrophic pyloric stenosis

Case study 8.4

Isaac

Isaac is a 5-week-old boy who has presented at the emergency department after a referral from the early childhood nurse. Isaac’s
mother is distressed, as the nurse has told her that Isaac has not put on any weight and is sleeping more than expected. Isaac’s mother states that he has regularly vomited after breastfeeds, but in the last week these incidents have become worse and the vomiting is forceful, ‘like a fire hose’. On further questioning, Isaac’s mother states that the vomit is milky and that otherwise he has been well. Over the last few days, he has seemed less active. His nappies are wet when changed; however, she is now only changing two or three per day, and his bowels are opening only once per day.

On examination, Isaac is noted to be pale and his skin is tented, almost like it is too much for his frame. Isaac is pale and sleeping in his mother’s arms. His vital signs are heart rate 172/min, respiratory rate 35/minute, per axilla temperature 36.9ºC and capillary refill of three seconds.

Infants and children may present to hospital with signs and symptoms of acute illness that will result the need for surgical correction. The nurse will need to provide care for both the preparation to operating theatre and post-operative management. Chapter 10 will provide discussion of these nursing considerations.

Pyloric stenosis occurs in approximately three to four of every 1000 infants, and as such is one of the more common surgical interventions of early infancy (Demain, Nguyen & Emil, 2009; Hunter, 2015). This condition commonly presents in males between the ages of 2 and 6 weeks where parents describe an infant who initially was thriving well, but progressively develops increasing forceful or projectile non-bilious vomiting (Demain, Nguyen & Emil, 2009; Hunter, 2015). For a reason that remains unclear, the muscles of the pyloric become thickened and do not
allow progression of stomach contents to the small intestine, effectively creating a blockage.

There are many disorders that mimic this condition, including gastric reflux disease and malrotation of the intestine and gastroenteritis. As can be seen in the case study above, these children present as acutely unwell, with signs of dehydration and electrolyte imbalance. These clinical signs require emergency management. While the child can have this obstruction surgically corrected, this cannot be attended to until fluid and electrolyte imbalances are repaired.

**Reflection point 8.5**

Case Study 8.4 shows a child requiring acute nursing and medical management. He has a diagnosis of pyloric stenosis. Review the findings in the case study and the information provided in this chapter and Chapter 6 to develop a nursing care plan for Isaac. Outline your nursing priorities and interventions. For example, what nursing assessments will need to be undertaken? Which would be the most appropriate intravenous fluid to treat dehydration?

**Summary**

- Acute viral infections are common in childhood. Although most cause only mild illness, some children will require nursing and medical care in a hospital setting.
- The approach to nursing assessment needs to take the developmental differences in infants and children into consideration.

- Fever, dehydration, hypoxia and pain are common reasons for children to require nursing care and intervention.

- Nursing care needs to consider the age and development of the infant or child, as well as the needs of the family.

**Learning activities**

8.1 Clinical practice guidelines (CPG) or evidence-based practice guidelines (EBPG) are often used to guide practice in acute-care settings. These guidelines are developed by expert groups of clinicians and researchers who have systematically reviewed and evaluated evidence for best practice. Following this, the expert groups have determined and then published the best recommendations, information and advice to assist health professionals to assess and intervene in the care and treatment of children with a range of conditions.

In this chapter, you have read several case scenarios of children with different presenting symptoms. Undertake an internet and database search for local and international CPG and EBPG for the care of a child with one of these conditions.

- Read the guidelines. Are they similar or different?

- Do they address all aspects of the condition, including assessment, treatment, nursing care and after care?

- Which expert groups have contributed to their development?
• What level of evidence or literature review has been undertaken in the preparation of the guideline?

8.2 Read the case scenarios for the children in this chapter. For each child, consider your response to the following questions:

• What key assessments and observations would you perform?
• How often would you perform these assessments?
• What changes might indicate that the child’s condition is deteriorating?
• What changes might indicate that the child’s condition is improving?
• What interventions would you include to meet the child’s emotional needs during hospitalisation?

Further reading

Obtain practice guidelines and policies from your local health service on their approaches to managing acute illness in children.

Refresh your knowledge of nursing interventions for acute illness using a core nursing textbook.

A wide range of websites can be found with clear photographs and information on rashes in childhood.

• The Centers for Disease Control and Prevention (CDC) is an internationally renowned, leading public health organisation in the United States, with responsibilities for the prevention of disease, injury and disability. The links below takes you to information

- Medicinenet is a reputable website based in the United States that provides detailed and relevant information about diseases, health and illness. The following link takes you to a slide show of images, including children with rashes:
- Icon Pediatrics is a private pediatric practice based in the United States, with an excellent web page that contains resources about anaphylaxis and allergy:
- The Ministry of Health in NSW provides a useful fact sheet on infectious diseases in childhood:
- The *British Medical Journal* (BMJ) is a leading international peer-reviewed medical journal and a reputable source of research and clinical evidence. The following link takes you to a search of childhood rash information provided by the journal:
References


Bai, J, Hsu, L, Tang, Y & van Dijk, M 2012, Validation of the COMFORT Behavior scale and the FLACC scale for pain assessment in Chinese


Offringa, M & Newton, R 2012, Prophylactic drug management for febrile


Russell, K et al. 2011, Glucocorticoids for croup, Cochrane Database of Systematic Reviews, 1, CD001955.


Tibballs, J & Watson, T 2011, Symptoms and signs differentiating croup


Fever – In most cases, measurements around 38°C (centrally measured) and higher are regarded as a fever

Anti-pyretic medications – These include paracetamol and non-steroidal anti-inflammatory medications such as ibuprofen; they are used to reduce fever

Body surface area (BSA) – A calculation of the surface area of the human body, expressed in square metres. BSA may be calculated using
software or a nomogram. In order to calculate BSA, an accurate weight and height/length of the patient is required.
Learning objectives

In this chapter you will:

- Develop your understanding of evidence based nursing assessments and interventions used in the care of acutely ill young people
- Develop your understanding of the aetiology, signs and symptoms of key acute illnesses experienced by young people in Australia
- Consider the developmental needs of young people in the planning and implementation of nursing care
- Explore the impact of illness and hospitalisation on young people
Introduction

In this chapter, we focus on the nursing care of young people, or adolescents. The transition to adolescence is a complex and critical period of development, with significant social, emotional and physical changes. Similar to childhood, adolescent development and maturation is complex, and differs between individuals. When planning nursing care, consideration for the individual adolescent, their characteristics and their stage of development is essential.

The reasons why adolescents require admission to hospital are more likely to be related to an injury or chronic condition. While most injuries are mild, and can be managed at home by parents, there are times when care and treatment for injury or illness results in the admission of the young person to hospital. The nursing care of children and young people with a chronic condition is addressed in Chapter 10. In this chapter, we will focus on the care of young people who need nursing care due to common acute injuries. In addition, the management of young people with appendicitis will also be explored in this chapter, as the peak incidence of this condition occurs in young people. Adolescence is a time when many young people begin to experiment with alcohol and other substances, and this can result in acute and unexpected illness. Thus the management of a young person with alcohol ingestion is also reviewed.

Key issues for young people during hospitalisation
Injury, illness and admission to hospital can be significant interruptions in the life of a young person. Wherever possible, we do our best to minimise the disruption by avoiding admission and providing ambulatory care in the community when it is available and appropriate to do so. However, some situations do require admission; when this occurs, ideally a young person is best cared for in an adolescent unit – an environment that understands the unique psychosocial and physical needs of adolescents.

Nurses and other health-care professionals need a good knowledge and understanding of adolescent development, and need to be confident when communicating with adolescents and their families (Sawyer et al. 2013). Unfortunately, adolescents do not always feel that their specific age-related needs are met by health-care services, and health professionals often lack confidence is working with young people (Jarrett et al. 2011; Sawyer et al. 2013). Young people have different recreation and social interaction needs from either young children or adults (Hutton, 2010; Steinbeck, Towns & Bennett, 2014). In addition, young people can become more self-conscious about their bodies, and may want a greater sense of privacy and control over their environment. However, adolescent-specific services, such as an adolescent ward, are a rare commodity in health care, and the adolescent is to some extent marooned between paediatric services, which are predominantly geared to the care of younger children, and adult services, which are most often used by people over 65 years of age. When adolescent health-care services are not available, then individual needs and consideration of preferences should be taken into account when assessing whether to admit adolescents to either paediatric or adult wards. For example, while it may be appropriate to have the ward lights out and everyone settled to sleep by 8.00 pm for younger children, young people may be more inclined to stay up later at night, and sleep in
later in the morning, and may be disturbed by infants who would normally wake during the night.

While still often under the care of their parents, young people are beginning to perceive themselves as individuals within a family, and may have different views regarding access to information, care and consent from those of their parents. At the same time, parents are adjusting to the increasing independence of their growing child. Both parents and adolescents need skilled and empathic health-care professionals who are sensitive to the complex and dynamic nature of adolescent–parent relations.

**Injuries**

Injury is a leading cause of hospitalisation for children and young people in Australia (Pointer, 2014). In children aged 10–14 years of age, approximately 16 per cent of all admissions to hospital are related to injury (Pointer, 2014). According to statistics from the Australian Institute of Health and Welfare (AIHW), the most common cause of injuries in this age group is a fall – for example, falling from playground equipment (Pointer, 2014). Rates of injury are also higher in rural and remote areas and for Aboriginal and Torres Strait Islander children and young adults (Harrison, Berry & Jamieson, 2012; Pointer, 2016). Young people who live in a remote area are twice as likely to sustain an injury that requires hospitalisation compared with young people living in major cities (Harrison, Berry & Jamieson, 2012).

When it comes to young people aged 15–17 years, self-harm is one of the primary reasons for admission to hospital. Girls of this age group are also more likely to be injured as a result of intentional self-harm compared
with other children (Griffin et al., 2014). This is also reflected in the hospital admission rates for self-harm, with young girls accounting for 35 per cent of admissions to hospital while boys only account for 4 per cent (Pointer, 2014). It is important to highlight that self-harm is often associated with other psychological factors and negative life events – for example, depression and suicide attempts by a family member (Doyle, Treacy & Sheridan, 2015). Hospitalisation for a physical injury may be an opportune time to intervene, or at least assess for a mental health problem. See Chapter 7 for more details regarding mental health.

**Head injury**

### Case study 9.1

**Maddie**

Maddie is 14-year-old girl who sustained serious injuries after a fall on her farm in rural Australia. She was standing on the roof of a small shed when the roof gave way; she fell approximately 2 metres, landing on the ground. She sustained a closed head injury with a witnessed loss of consciousness for three minutes, fracture of the left femur, chest bruising, cuts and grazes. Maddie was initially assessed in a local hospital. On arrival, she was tachycardic with a heart rate of 120, and her blood pressure (BP) and respiratory rate were within limits for her age. Maddie’s initial Glasgow Coma Scale (GCS) was 12 (eyes 3, verbal response 4 and motor response 5). The severity of her injuries indicates that she may require a computerised tomography (CT) scan of her brain (NICE, 2014; New South Wales Health, 2011). CT scanning was not available at Maddie’s local hospital, so a decision was made to
contact the relevant retrieval service. She was transferred to the high-dependency unit of a tertiary referral centre. On arrival in the unit, Maddie had a GCS of 14, vital signs within limits for age and was complaining of a persistent headache.

Most head injuries that occur to children and young people are minor, and most will not have significant intracranial pathology (Davis & Ings, 2015). However, any head injury can result in significant harm. It is therefore important to monitor and assess the child or young person closely after the event. The extent or degree of severity of head injury should determine the initial response. Head injuries are traditionally classified by severity into mild, moderate and severe. Maddie’s injuries are consistent with a moderate head injury as she had a GCS of 12 at the local hospital (New South Wales Health, 2011).

Head injuries can be categorised as internal (involving the skull or the brain) or external (involving the scalp). In Case Study 9.1, Maddie’s injury involved trauma to the brain; she did not suffer any injuries to her scalp. The likely severity of a head injury can be estimated according to risk factors (see Table 9.1) that would categorise the injury as high, intermediate or low risk. In Maddie’s case, her injuries are consistent with an intermediate risk: the injury occurred as a result of a fall of 2 metres, there was a loss of consciousness of three minutes, she did not vomit and her behaviour is normal. She does have a persistent headache and a score on the Glasgow Coma Scale (GCS) of 14, however, and thus requires close observation and ongoing neurological assessment (New South Wales Health, 2011).

Table 9.1 Risk groups in head injury
<table>
<thead>
<tr>
<th>Low risk (all features)</th>
<th>Intermediate risk (any feature/not low or high risk)</th>
<th>High risk (chalice criteria) (any feature)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>History</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Witnessed loss of consciousness</td>
<td>Nil</td>
<td>&lt;5 minutes</td>
</tr>
<tr>
<td>Anterograde or retrograde amnesia</td>
<td>Nil</td>
<td>Possible</td>
</tr>
<tr>
<td><strong>Behaviour</strong></td>
<td>Normal</td>
<td>mild agitation or altered behaviour</td>
</tr>
<tr>
<td>Episodes of vomiting without other cause</td>
<td>Nil or 1</td>
<td>2 or persistent nausea</td>
</tr>
<tr>
<td>Seizure in non-epileptic patient</td>
<td>Nil</td>
<td>Impact only</td>
</tr>
<tr>
<td>Non accidental injury (NAI) suspected</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>--</td>
<td>---</td>
</tr>
<tr>
<td>Headache</td>
<td>Nil</td>
<td>Persistent</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Nil</td>
<td>Present</td>
</tr>
<tr>
<td>Age</td>
<td>&gt;1 year</td>
<td>&lt;1 year</td>
</tr>
</tbody>
</table>

**Mechanism**

<table>
<thead>
<tr>
<th>Motor vehicle accident (MVA) (pedestrian, cyclist or occupant)</th>
<th>Low speed</th>
<th>&lt;60 km/h</th>
<th>&gt;60 km/h</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fall</td>
<td>&lt;1 m</td>
<td>1–3 m</td>
<td>&gt;3 m</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Force</th>
<th>Moderate impact or unclear mechanism</th>
<th>High-speed projectile or object</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low impact</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Examination

<table>
<thead>
<tr>
<th>Glasgow Coma Scale (GCS)</th>
<th>15</th>
<th>Fluctuating 14–15</th>
<th>&lt;14 (or &lt;15 if under 1 year old)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focal neurological abnormality</td>
<td>Nil</td>
<td>Nil</td>
<td>Present</td>
</tr>
<tr>
<td>Injury</td>
<td></td>
<td></td>
<td>High-risk features – for example, scalp haematoma in &lt;1 year of age (see below)</td>
</tr>
</tbody>
</table>

### Placement

<table>
<thead>
<tr>
<th>Observation area</th>
<th>Anywhere in ED</th>
<th>Acute area in ED</th>
<th>Acute or resuscitation bay</th>
</tr>
</thead>
</table>
**Observations**

- Respiratory rate, oxygen saturations
- Pulse, blood pressure
- Temperature
- GCS, pupillary response and size, limb strength
- Pain assessment
- Sedation score

<table>
<thead>
<tr>
<th>Observations</th>
<th>Hourly observations until discharge</th>
<th>Half-hourly observations for four to six hours until GCS 15 sustained for two hours, then hourly observations until discharge</th>
<th>Continuous cardio-respiratory and oxygen saturation monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Revert to half-hourly observations/continuous monitoring if signs of deterioration occur</td>
<td></td>
<td>BP and GCS every 15 to 30 minutes</td>
</tr>
</tbody>
</table>
Assessment and management

Assessment – both at the time of the injury and over time – is a critical element in the nursing management of people who have sustained a head injury. A rapid neurological assessment of level of consciousness can be undertaken using AVPU: is the patient alert, verbal, responding to pain or unconscious? The AVPU scale correlates well with the GCS and enables clinicians to make a rapid assessment (Hoffman et al., 2016). This rapid assessment assists clinicians to assess the severity of the head injury; however, as mentioned above, we should always be mindful that it may take several minutes or hours for the full extent of a head injury to become apparent.

In addition to the rapid initial assessment of consciousness, a more in-depth assessment should be performed using the GCS. While a modified GCS is appropriate in children, in young people the standard GCS should be used. In addition to these assessment tools, clinicians should also consider the opinion of parents in neurological assessment. Parents know their children well, and are often the first to notice that all is not well. If a parent is concerned about a change in the behaviour of their child, then we should also be concerned. In addition to changes in behaviour, clinicians
should also be alert to any signs of generalised or local seizure activity – clear signs that the injury is severe or worsening. For more details on neurological assessment, refer to Chapter 6 on recognition of the signs of a deteriorating child.

Frequency of neurological assessment and the timeframe for close observation will be determined by the estimated severity of the head injury. Initially, at least hourly neurological and vital observations are required, though these should be more frequent if a higher severity of head injury is suspected. If the head injury is assessed as mild and observations are normal, most patients are discharged after approximately four hours. If there is concern that the injury is of moderate severity, a longer period of observations and a CT scan may be required. Children and young people may need to be kept to nil by mouth at least initially, pending decisions about further investigations or surgery that may require administration of an anaesthetic.

Not surprisingly, head injuries can be painful; however, clinicians can be concerned about the use of analgesia in patients with head injury – especially analgesics with a known sedative effect. When considering what analgesia to give a patient with head injury, consideration should be given to factors such as the patient’s clinical signs, the need for analgesia and the patient’s pain score (Trauma Victoria, 2016). For mild pain, an oral analgesic (for example, paracetamol) that does not cause sedation may be appropriate. For more severe pain, consideration may be given to using opioids, but these should be administered with care. The sedative effects of opioids may mask deterioration in level of consciousness due to the head injury. The New South Wales Clinical Practice Guidelines on management of patients with head injury (New South Wales Health, 2011) recommend that a sedation assessment be performed in addition to neurological
assessments such as GCS to monitor the sedative effect of opioids administered in people with head injury.

Another very important aspect of assessment of head injury is the history of the injury. It is important that clinicians give consideration to whether the severity and location of the head injury accord with the history of the injury that is provided. Sadly, we have to consider that a head injury in a child or young person may be non-accidental. Clinicians need to maintain an open mind to this possibility during assessment. For further details on non-accidental injury, and child abuse and neglect, see Chapter 2.

For young people like Maddie, serious injuries incurred in a rural area usually result in retrieval to a city or regional hospital, distant from their home, as specialist neurological services are centrally located in cities. This can mean additional concerns for young people and their families, who are already frightened or anxious about the extent of the injury sustained. In addition, families in this situation incur additional costs associated with living away from home while they care for their child in a city hospital. In some instances, one parent may need to stay with the rest of the family at home while the other parent travels with their injured child. Nurses need to ensure that they support families in this situation. The importance of caring, flexible and understanding health professionals, facilities and resources to enable families to stay with their injured child, or the means for them to stay in contact from a distance, is vital. Preparing young people and parents for discharge after head injury is also important. Make sure that parents and young people are clear regarding signs that would require them to return for further assessment.

**Musculoskeletal injuries**
Musculoskeletal injuries are a frequent reason for children and young people to require hospital care. Musculoskeletal injuries that may occur include strains, sprains, joint dislocations and fractures. For young children, these injuries commonly arise from play equipment (Mulligan, Adams & Brown, 2016; Pointer, 2014). It is interesting to note that with the introduction of trampoline parks, hospitals are seeing an increase in injuries sustained on trampolines (Kasmire, Rogers & Sturm, 2016; Mulligan, Adams & Brown, 2016). In older children and young people, the injury may arise from sport and recreational activities or from motor vehicle accidents (Pointer, 2014). In both children and young people, attention should be paid to correlation between the injury and the history of how the injury occurred. As mentioned previously, clinicians should always be mindful that an injury may be the result of physical abuse of the child or young person (Emalee et al., 2014). For further information about child abuse, see Chapter 2.

A fracture of the bone will occur when the force exerted on a bone is greater than the strength of the bone is able to resist. In younger children, bone formation is still immature. The bones are more porous and the periosteum is thicker, so the bone is compliant and thus less likely to completely break in response to a greater force. For these reasons, younger children and infants will be more likely to have an incomplete fracture, such as a greenstick injury. By early adolescence, the bone is much more dense, and complete fractures are more likely (Curtis & Ramsden, 2016). See Figure 9.1.
When caring for children or young people with musculoskeletal injuries, it is important to consider interventions such as splinting or elevating the limb to help reduce their pain. Applying splints to the injured limb, such as a backslab, reduces pain and prevents further damage to bone and soft tissues around the fracture (Curtis & Ramsden, 2016). Analgesia should be administered based on the severity of pain; this should be assessed using an appropriate age-based pain scale such as the Faces Pain Scale or a linear scale (New South Wales Health, 2016).

Infection control is an important consideration for management of children with an open fracture. The general principles of caring for a child with an open fracture include covering the wound with an appropriate dressing and the administration of a broad-spectrum antibiotic and tetanus prophylaxis. It is important that the wound site is thoroughly cleaned to prevent bacteria invading the fracture site; this is usually done under a
general anaesthetic (Schaller & Calhoun, 2016). Depending on the nature of the fracture, open or closed reduction of the fracture and application of traction or plaster cast under anaesthetic may also be required, and therefore pre-operative and post-operative care should be considered.

Frequent and accurate neurovascular observations are an essential component of nursing assessment in the care of people with a fracture. These assessments are somewhat easier in young people than younger children, as young people are more likely to understand the questions put to them as part of the assessment. The main components of neurovascular assessment include the five Ps: pain, paralysis, paresthesia, pulses and pallor (Curtis & Ramsden, 2016; Shields & Clarke, 2011).

Regular pain assessment should be undertaken, as increasing pain can indicate neurovascular impairment. Increasing analgesic requirements can be one of the signs of compartment syndrome in children; this needs to be considered particularly in children who are not able to verbalise their pain accurately (Hosseinzadeh & Talwalkar, 2016). We also need to consider whether the pain is from the original injury and the need for appropriate analgesia to be administered as required. The child or young person should be asked to move their limb distal to the injury. Be aware that pain may inhibit movement, so it is important to ensure that adequate analgesia is administered. Sensation, pulses and colour should be assessed in the affected limb and compared with those in the unaffected limb. The limb pulses should be palpated for rate and quality at a site that is distal to the injury, traction or cast. If pulses are absent or unable to be assessed due to a plaster cast, then perform capillary refill assessment. Capillary refill time should be less than two seconds. The colour and swelling of the limb are also important indicators of vascular impairment – a swollen cool, pale or mottled limb is a concerning sign (Curtis & Ramsden, 2016; Shields &
Prior to discharge, young people and their parents should be given information about the signs of neurovascular impairment. In addition, if a plaster cast is applied, cast care instructions should be discussed, including protection from water, physical damage and the risk of the insertion of foreign objects into the cast.

**Abdominal pain**

**Case study 9.2**

**Bo**

Bo is a 15-year-old girl who presents to the general medical practice accompanied by her mother and older sister. Bo has had abdominal pain for several days, but it has increased in severity over the past 12 hours. During examination, it becomes apparent that the pain is difficult to localise, although it increases when Bo moves. Bo has not eaten or had a drink since yesterday. Her mother reports that she has been ‘off her food’ for a day or two. Her bowel movements have not changed recently. Bo has a low-grade fever (37.8°C), a heart rate of 110/minute and blood pressure of 95/55 mmHg. The medical officer is not certain of the cause of the pain, but considers that it may be early appendicitis and refers Bo to the emergency department of her local hospital. The team at the hospital decides that there are reasonable grounds to suspect appendicitis. Bo is prepared for transfer to theatre for an
Children and young people with abdominal pain are a common group seeking care in emergency departments and general practice. It can be difficult to determine the cause of such pain, as there are many potential causes, and the child or young person may find it difficult to pinpoint the exact location of the pain and describe it clearly. Symptoms of abdominal pain in younger children are less specific and more difficult to localise, whereas a young person should be able to localise and describe the pain in more detail. However, the nature of abdominal pain seems to vary considerably between individuals and conditions. Abdominal pain may indicate a range of conditions from mild issues such as constipation to more serious problems that are the result of acute conditions, such as appendicitis or trauma.

**Assessment and management**

Assessment of the child or young person with abdominal pain is essential, especially when the cause is not clear. While in many cases abdominal pain may resolve or be related to relatively non-urgent conditions, there is a possibility that the symptom of pain indicates a more serious and urgent problem.

Chapter 6 outlines the principles for recognising and responding to signs of deterioration. These principles are the framework that we would use in practice for Bo – monitoring cardiovascular stability through the measurement of vital signs such as pulse and blood pressure, and the assessment of other clinical signs including colour, behaviour, peripheral circulation and pain.
In the past, clinicians were reluctant to give analgesia to relieve abdominal pain until a diagnosis of the cause of the pain was made. Contemporary clinical guidelines indicate that there is no evidence to support the withholding of analgesia in children or young people with acute abdominal pain, nor does the use of analgesia impede diagnosis or treatment (National Institute of Clinical Studies, 2011; New South Wales Health, 2013).

**Appendicitis**

Acute appendicitis is the most common surgical emergency in children and young people, although in some cases appendicitis may be treated conservatively. Approximately 16 per cent of people in developed countries will have an appendicectomy during their lifetime, with the peak incidence between the age of 8 and 14 years (Bradbury, Forsythe & Parkes, 2012). Although it is relatively common compared with other abdominal conditions, the causes of acute appendicitis are not fully understood. It may be related to some degree of obstruction of the appendix that triggers an inflammatory response in the mucosa of the appendix (Agency for Healthcare Research & Quality, 2015). The inflammation may cause venous congestion and diminish arterial blood supply, leading to ischaemia and infarction (Bradbury, Forsythe & Parkes, 2012). If this does not resolve, appendicitis can lead to perforation and sepsis.

There is no definitive test to diagnose appendicitis, apart from direct visualisation via laparoscopy – a rather invasive diagnostic tool! Thus clinicians rely on clinical signs and symptoms, and blood test results such as white blood count, in deciding whether to proceed to laparoscopy and, if required, appendicectomy, or to wait, watch and observe to see whether
the pain decreases or increases, and whether other symptoms develop (Agency for Healthcare Research & Quality, 2015). In addition to abdominal pain, individuals with appendicitis may have nausea, vomiting, diarrhoea, fever, pallor or abdominal distension (Howell et al., 2010). None of these signs or symptoms is conclusively indicative of appendicitis – they can indicate other conditions such as inflammatory bowel diseases, mesenteric adenitis, pelvic inflammatory disease or ectopic pregnancy, to name just a few.

As some of the symptoms of appendicitis may also be symptoms of gynaecological disorders, it is important to establish whether the young person has commenced menstruation and whether they are sexually active in order to exclude pregnancy. It is essential that discussions about puberty, sexual activity and any related tests are handled with great tact and diplomacy. Please recognise that the young person may not be willing to disclose their sexual history in front of parents, friends or family. Furthermore, young people may deny that they are sexually active even when they are.

**Reflection points 9.1**

Imagine that you are required to ask Bo to provide a urine sample for a pregnancy test. Think about who might be present, the environment you may be in and the words you might use.

- What will you say to Bo?
- What will you do to maintain her privacy?
- What right does Bo have to consent to or refuse this urine sample?
Pre-operative care

Adequate preparation for operations is an essential and important role for nurses in the care of children and young people. For children and young people who require elective procedures, there is often sufficient time to support parents to be the main ‘preparers’ for the child or young person, or at least for parents to provide the initial explanation to their child about what will happen. Emergency procedures such as the one Bo requires are often a shock to the parent, and they may be unable to take in, process and use the information we provide to explain to their child what is about to occur to an adequate level. In either event, the onus is on medical and nursing staff to ensure that everyone – both the parents and the young person – is clear about what is required and what is likely to occur. Older children and adolescents may have a more sophisticated understanding of the workings of their insides than younger children; however, it is important to remember that the level of understanding can vary considerably between individuals when providing explanations about pre-operative procedures and post-operative care (Panella, 2016).

Apart from psychological preparation, physical preparation is also required. This may include nil by mouth for a period of time, showering prior to the procedure and dressing in a theatre gown. These procedures are very familiar to nurses used to caring for adults, but it is important to remember that, for most young people like Bo, this would be their first experience of surgery. Seemingly strange practices such as the requirement
that patients do not wear any underwear to theatre can be unsettling for a young person who is modest and conscious of their body. A young person such as Bo may become quite anxious once the decision is made to operate, and therefore consideration may also be given to some form of pre-operative sedation.

Obtaining informed consent for procedures is an important part of preparation. Details of the legal and ethical issues that arise in obtaining consent are dealt with in Chapter 2.

**Post-operative care**

The principles of post-operative care are similar for children, young people and adults. The priority of nursing care in the immediate post-operative period is to monitor for any adverse effects of the surgical intervention and/or anaesthesia, including airway obstruction and haemorrhage. Initially, continuous cardio-respiratory monitoring is indicated until the young person rouses and then, once they are awake, frequent assessment of respiratory and cardiovascular status – including heart rate, respiratory rate, respiratory assessment, blood pressure and oxygen saturation – is required. The incision site should be observed for excess blood loss.

Pain management is an important component of post-operative care. By the time children reach early adolescence, they are able to describe and quantify pain with greater precision and detail. Pain-assessment tools, including the Faces Pain Scale or numerical rating scales, can be used with young people. Analgesics should be administered regularly to relieve pain and to facilitate early post-operative ambulation. **Patient-controlled analgesia (PCA)** is an excellent choice for young people, and can help to give them a sense of control over their post-operative care.
Alcohol poisoning

Case study 9.3

Ryan
Ryan is a 14-year-old boy who has been at a party with a large group of friends. During the evening, Ryan smoked cannabis and consumed a large quantity of alcohol. Over time, he became disoriented, vomited and eventually passed out. His friends were unable to rouse him. One of his friends called an ambulance, and Ryan was assessed and transferred to the emergency department of the local hospital. On arrival at hospital, Ryan is lethargic, confused and difficult to rouse, responding only to painful stimuli, with a GCS of 11 (eyes 2, verbal response 4, motor response 5). His pupils are equal and reacting briskly to light. His vital observations include heart rate 115 per minute, respiratory rate 18 per minute, BP 90/50 mmHg and SaO2 96 per cent in room air. He smells strongly of vomit and alcohol. Bloods are taken, and the results reveal a blood alcohol level of 55 mmol/L.

According to the National Drug Strategy Household Survey of 2013, the most commonly used drugs in young people aged 12–17 years are cannabis, alcohol and tobacco (AIHW, 2014). The age at which young people first use cannabis is declining, with the current age for first time cannabis use around 16 years (AIHW, 2014). This puts Ryan in Case Study 9.3 in a younger age group than the average Australian. When it comes to alcohol, approximately three of every four Australian secondary students aged 12–17 years will have tried alcohol, and the rate of alcohol
consumption increases with age. By the age of 16 years, approximately 13 per cent of young people report an episode of binge drinking in the past seven days, consuming more than four standard drinks on one day (White & Bariola, 2012). Consequently, some young people may consume harmful amounts of alcohol, resulting in alcohol intoxication and poisoning, and requiring acute care in a hospital setting.

During adolescence, the brain is still developing and young people can put themselves at risk of long-term deficits if they drink alcohol regularly. The ingestion of alcohol in this age group has been shown to lead to a decline in cognitive abilities such as memory loss and visuospatial abnormalities (Hanson et al., 2011; Risher et al., 2015). Alcohol can also lead to neurological deficits when it is ingested initially, as it causes central nervous system (CNS) depression. The sedative effects of alcohol, in addition to the risk of vomiting when intoxicated, mean there is a significant risk of respiratory arrest.

**Assessment and management**

Immediate care of the young person with alcohol poisoning begins by maintaining a clear airway. In Case Study 9.3, Ryan is at risk of aspirating vomit, and therefore should be positioned on his side in the recovery position. The next important priority is to monitor level of consciousness. We would expect this to improve over time, as Ryan has stopped ingesting alcohol and the residual alcohol in his blood should be metabolised. Administration of intravenous fluids may be required to maintain hydration and replace fluids lost from vomiting.

Once the initial acute phase has resolved, consideration needs to be given to psychosocial issues. Psychosocial screening of the adolescent can be undertaken, using a recognised framework such as the HEADSS
framework, which assesses home circumstances, their engagement in education/employment, activities with peers, use of drugs, sexuality and mental health (suicide risk, self-harm and depression).

The HEADSS psychosocial screening tool provides a useful framework for the assessment of adolescent risk and sources of support. However, asking a young person about their social, sexual and physical wellbeing can be difficult for beginners. The Royal Children’s Hospital in Melbourne provides a useful clinical guideline for engaging with adolescents, using the HEADSS tool. See www.rch.org.au/clinicalguide/guideline_index/Engaging_with_and_assessing_the_adolescent_patient.

Abuse of alcohol and illicit drugs such as cannabis can be an indicator of psychosocial or mental health problems in the young person. Some young people may use substances such as alcohol to deal with feelings of sadness, anxiety or despair. It is important that the young person’s mental health and wellbeing are assessed prior to discharge. An admission related to alcohol abuse should be seen as an opportunity to provide education and support for a young person to deal with alcohol abuse and any related psychosocial issues, and refer them to appropriate community-based services.

Reflection points 9.2

People from different ethnic and cultural backgrounds often have different perspectives on adolescence, particularly in relation to social and emotional development. In a country such as Australia, with a diverse multicultural population, there can be a range of views on what might be appropriate behaviour, rules and
expectations regarding adolescents. Take a few minutes to think about the following points:

- What is your ethnic and cultural background?
- In your family, would Ryan’s drinking be accepted or tolerated, or neither?
- How might your background impact on your perception of Ryan’s behaviour?
- If you found Ryan’s behaviour confronting, what could you do to ensure that your personal judgement of this behaviour did not impede the care you provided to Ryan?

### Summary

- Adolescence is a time of transition for both the young person and their family.
- The health-care needs of adolescents are different from those of young children and adults, and care should be tailored to their needs.
- Young people should be cared for in an environment that is best able to meet their special developmental needs.
- Injury is a common reason for hospitalisation of young people, and some will require admission to hospital for nursing care and medical treatment.
- Injuries may indicate underlying psychosocial and mental health issues in young people.
Learning activities

9.1 Even though the proportion of young people requiring hospital care is substantial, not all hospitals or health-care services provide adolescent-specific services. In recognition of the special needs of children and adolescents, professional and consumer organisations have worked collaboratively to develop guidelines and standards in order to encourage and guide health-care services on how best to meet the special needs of children and young people, including adolescents. One such guideline was developed and published in 2008, and can be accessed online at www.awch.org.au/pdfs/Standards_Care_Of_Children_And_Adolescents.pdf (Royal Australasian College of Physicians, 2008). Once you have read the standards, consider the following questions:

- What age group of young people do you care for?
- What specific facilities or policies are used to support the care and wellbeing of young people in the hospital or ward where you work?
- How could the environment or service in which you work be modified to better meet the needs of young people?

9.2 Read the case scenarios for the young people in this chapter. For each young person, consider your response to the following questions:

- What key assessments and observations would you perform?
- How often would you perform these assessments?
- What changes might indicate that the young person’s condition is deteriorating?
• What changes might indicate that the young person’s condition is improving?

• What interventions would you include to meet the young person’s emotional needs during hospitalisation?

**Further reading**

• Obtain and review practice guidelines and policies from your local health-care service on their approaches to the care of young people with acute illness.

• Refresh your knowledge of nursing interventions for acute injury, and pre-operative and post-operative care using a core nursing textbook.

**References**


**Adolescence** – Most commonly considered the period of time between the onset of puberty and the time an individual is legally recognised as an adult – anywhere from 10 to 18 years. However, it is not one discrete period of development; there is considerable individual variation in development, and evidence that final brain development is not complete until the mid-twenties.

**PCA or patient-controlled analgesia** – is a form of analgesia where administration is controlled by the patient. In acute care settings such as paediatrics, it is usually intravenous analgesia administered via special intravenous pump designed to administer medications by the patient, such as opioids, by bolus injection. This form of analgesia is well suited to patients older than 6 years, who have appropriate cognition regarding their pain and the use of the device.
Evidence-based nursing assessments and interventions: The child and young person with a chronic illness

Donna Waters and Helen Stasa

Learning objectives

In this chapter you will:

- Develop an understanding of some common chronic conditions experienced by children and young people in Australia
- Review evidence-based symptom assessment and interventions associated with common chronic conditions experienced by Australian children and young people
- Consider the developmental needs of children and young people in planning and implementing nursing care for chronic medical conditions
Introduction

As a paediatric nurse, you will frequently care for children and young people with chronic conditions. Your initial contact may be during routine assessment, at diagnosis or during subsequent treatment (such as for the management of childhood cancers or type 1 diabetes). You may also be part of a team managing an acute illness in a child or young person with a chronic condition, as might occur during an exacerbation of asthma or a urine infection in a child with spina bifida. Depending on your role, your involvement may extend to a clinic, home, school or community – for example, if you are running a healthy weight program. If you work within one organisation or within one specialty practice for any period of time, you may form long-term relationships with chronically ill children and their families, becoming part of their lives as they grow into young people and adults – or, inevitably for some, until the end of their lives.

It is not usual to associate children and young people with chronic conditions, especially as some definitions relating to adult illness (such as cardiac disease) imply that chronic diseases are those for which action can be taken to prevent their occurrence (ABS, 2015a). However, the most recent available estimates indicate that between 2007 and 2008, 37 per cent of children and young people in Australia had at least one long-term chronic condition. This figure equates to more than 1.5 million future Australian adults (ABS, 2009). Asthma, diabetes and cancer are the most
common chronic medical conditions affecting children in Australia, collectively accounting for 20 per cent of the burden of disease among children aged 0–14 years (AIHW, 2012), but the range of chronic conditions affecting children and young people is much broader. There are many other congenital (present at birth – for example, cleft lip or palate, hearing and vision impairment, autism and heart defects) and acquired conditions (for example, accidental brain or other injury, and surgical or treatment complications) that significantly impact the way a child lives, grows and functions within their family and community.

In Chapter 1, we described chronic conditions that affect Australia’s children and young people by prevalence – in other words, by measuring how common the condition is within a particular age group or population at any given point in time. We also discussed hospital separation rates as a measure of the burden of illness caused by chronic diseases. In addition, we identified that around 7 per cent of Australian children aged 0–14 years currently experience some type of disability, with almost 4 per cent experiencing a severe disability (AIHW, 2012).

There is also a great deal of variation within and between chronic conditions. For example, the causes of congenital heart disease (CHD) are multifactorial, with approximately 20 per cent of cases known to be associated with chromosomal abnormalities (Blue et al., 2012). The early surgical repair of simple structural problems like ventricular and atrial septal defects will effectively ‘cure’ these conditions; however, children requiring more complex repair of cardiac problems, such as Tetralogy of Fallot or transposition of the great arteries, are likely to require ongoing medical and surgical management into adult life (Khairy et al., 2010).

Any chronic condition has the potential to interrupt normal childhood growth, emotional maturation, education and social development (see Chapter 4), with symptoms, hospitalisations and treatments having both
immediate and long-term effects. The management of chronic conditions requires a multidisciplinary team approach, with integration of care and treatment, family support and involvement, and specific self-management education and involvement in decision-making. The physical, emotional, educational and social wellbeing of a child or young person with a chronic illness can easily be overlooked, with the focus being on their disease rather than on them as a developing person. While there are now a large number of online resources, blogs and chat sites for children and young people with chronic conditions, their siblings and carers, the effect on family economic and social functioning is likely to remain significant (see Chapter 11).

This chapter discusses the aetiology, signs and symptoms of some common paediatric chronic illnesses that you are likely to encounter in your work as a paediatric nurse. We begin with two conditions introduced in Chapter 1, asthma and diabetes, which remain the most common long-term conditions affecting children and young people in Australia. We also discuss some common congenital and genetic presentations. While your practice should always be based on the most up-to-date clinical practice guidelines and evidence-based recommendations, it is vital that you remain aware of any new research findings.

Further, it is important to remember that children and young people with chronic conditions, and their siblings, parents and carers, live with these illnesses every day. They are very often connected into increasingly sophisticated online and social networks, and are therefore likely to know much more about their condition, and the current recommendations for management, than you do. Therefore, your care of chronically ill children and young people must also include listening carefully to the experience and needs of the whole family and making decisions together. The second part of this chapter will explore the specific challenges faced by young
people with chronic illnesses in leaving the familiar environments and people of the paediatric setting to make the transition to adult health care.

### Reflection points 10.1

- Some children and young people living in remote and very remote regions of Australia have limited access to health and support services. What will be the likely impacts on their care and treatment if they also have a chronic condition? How can social and other media (e-health) improve the experience of children and young people with chronic conditions?

- Children and young people with chronic conditions are often more vulnerable to common childhood illnesses and may become very unwell during such episodes or exposures. What general health-promoting activities would you recommend to a young person with a chronic illness?

- For children and young people whose health management requires spending periods of time in hospitals and clinics, what impacts might this have on their education, and how might you be able to mitigate some of these effects?

### Chronic conditions

While it is not possible to explore all chronic conditions that might affect children and young people, this section discusses two of the most common chronic medical conditions of childhood – asthma and diabetes – as well as a common genetic disorder – cystic fibrosis (CF). These conditions offer
examples for which ongoing medical or surgical management, health maintenance and education for self-care, as well as significant health professional involvement in successfully transitioning to the adult care environment, are needed. You may find that some of these management strategies can be applied to the care of children and young people with other chronic conditions.

**Asthma**

Early results from the Australian National Health Survey 2014–15 report that around 12.4 per cent of Australian boys and 9.6 per cent of Australian girls aged 0–14 years had an asthma diagnosis (ABS, 2015b: 10). This makes asthma the most common long-term chronic condition affecting children and young people in Australia and one of the most common causes of hospital admission and visits to a general practitioner (GP). Despite being recognised as a distinct condition since the early nineteenth century, the underlying causes of asthma are still not well known. In the twenty-first century, asthma is a chronic condition that can be managed effectively with appropriate prevention treatment, avoidance or control of trigger factors, and medication. In 2011, 17 deaths in the 5–24 years age group were directly attributed to asthma (Poulos et al., 2014: 3).

The National Asthma Council of Australia (NACA, 2015) describes asthma as a chronic lung disease that can be controlled but not cured. Asthma is a heterogeneous condition characterised by chronic inflammation of the airways, airway hyper-responsiveness and intermittent narrowing of the airways, causing wheeze, chest tightness, shortness of breath and cough (or combinations of these) (GINA, 2016: 14). As a paediatric nurse, it is important that you are aware of, and follow, local protocols for the treatment of acute asthma. In general, a diagnosis of
Asthma should be considered in a child who presents with cough, wheeze or difficulty in breathing. A prolonged expiratory phase may be an early sign if wheeze is not present.

The New South Wales Ministry of Health Clinical Practice Guideline for the Acute Management of Asthma (Ministry of Health, 2012) identifies four common patterns of childhood asthma, with subsequent implications for the management of an acute attack and for ongoing asthma management (see Table 10.1).

### Table 10.1 Common patterns of childhood asthma

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Proportion of children With asthma</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infrequent, intermittent asthma</td>
<td>Approx. 70–75%</td>
<td>• Commonly triggered by upper respiratory tract infection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Acute illness lasts few days to one week; intervals more than six weeks apart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Symptom-free during interval</td>
</tr>
<tr>
<td>Frequent, intermittent asthma</td>
<td>Approx. 20–25%</td>
<td>• Intervals often less than six weeks apart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Minimal or no symptoms between intervals</td>
</tr>
</tbody>
</table>
Persistent asthma  
Approx. 5–10%

- Symptoms on most days including disrupted sleep and exercise intolerance

High-risk asthma  
< 5%

- Recurrent presentations
- Multiple asthma medication (including admission for intravenous treatment or steroids in past 12 months)
- Previous intensive care admission
- Re-presentation soon after discharge
- Coexistent medical condition
- Unresponsive to bronchodilator

It is likely that, rather than being just one condition, asthma represents a spectrum of conditions with different pathophysiology. Recognisable clusters of asthma presentations are sometimes referred to as asthma ‘phenotypes’ (GINA, 2016: 14) because they share similar clinical,
pathophysiological or demographic features. While asthma is most often associated with hypersensitivity to allergens, it is thought that environment, lifestyle, maternal nutrition and weight, and genetic factors also play a part in the development of childhood asthma. Ellwood and colleagues (2013) have recently reported on the potential protective effects of healthy eating on severe asthma.

**Nursing assessment and interventions**

An asthma attack may initially present following a period of recurrent or persistent illness, after exposure to allergens or, in those already diagnosed, may indicate a need for review of a current asthma plan. Judging the severity of an acute asthma attack is the most important part of the initial clinical assessment. Listening to the child and accompanying parent’s or carer’s interpretation of severity will greatly aid this assessment. The severity of the attack can also be measured by oxygen saturation, heart rate, ability to talk (if verbal) or cry, accessory muscle use and level of consciousness (Ministry of Health 2012; NACA, 2015). Any tachycardia, cyanosis, drowsiness or agitation with moderate to severe accessory muscle use is serious, and requires immediate medical intervention with close observation and review. A thorough clinical examination with a medical history inclusive of a family history of asthma, exposure to secondary tobacco or other environmental smoke, eczema or allergic rhinitis should be undertaken when the child’s condition is stable. In young children, it is important to exclude pertussis, bronchiolitis or pneumonia as differential diagnoses, and to consider the possibility of an inhaled foreign body as a cause of symptoms.

**Case study 10.1**
Harriet

Harriet is a 13-year-old girl with a history of asthma. She is brought into the emergency department by ambulance with severe shortness of breath. On arrival, she is conscious, only able to speak single words and very short of breath (RR 35 bpm). Her oxygen saturation on a Hudson mask is 92 per cent. Auscultation of her chest reveals an inspiratory wheeze and decreased breath sounds bilaterally.

Harriet is what some health professionals call a ‘frequent flyer’. She has a history of severe asthma and previous intensive-care admissions and intubation. She has been experiencing shortness of breath for four hours, and this is worsening. She had been nebulising with salbutamol every hour at home before her admission to hospital.

Despite receiving maximal therapy, Harriet, becomes drowsy and tachycardic (130 bpm) and desaturates further (SaO2 90%).

The treatment of asthma is individual, and highly dependent on the severity of the attack, but will usually include a symptom-control medication (such as an inhaled bronchodilator) and a preventer medication (commonly a low-dose corticosteroid or long-acting bronchodilator). Oral steroids and other inhibitor medications may also be used for acute attacks. In severe, acute asthma attacks like Harriet’s, bronchodilators (salbutamol, aminophylline or magnesium sulphate) and corticosteroids (hydrocortisone or methyl prednisolone) would be administered intravenously as she has shown no response to nebulised treatment. Because of her history (high-risk asthma; see Table 10.1), Harriet is transferred directly to the intensive care unit for continuous cardiorespiratory monitoring, blood gases and
Continuous nebulised salbutamol is delivered while intravenous access is established and medications commenced.

Following initial diagnosis, or an acute asthma attack, the further management of asthma is guided by the pattern and severity of symptoms. The general principles of asthma management aim to ensure that asthma is correctly diagnosed, and that the child or young person can maintain as normal a life as possible without interruption from asthma symptoms or the effects of asthma medications (NACA, 2015). For most children, young people and their parents or carers, this aim is facilitated by the shared development of an asthma management plan and maintenance of the lowest possible dose of medications to achieve good asthma control and prevent acute attacks. Preventer medications (often low-dose inhaled corticosteroids) are important, as these make the airways less sensitive by drying up mucus and reducing swelling, but they need to be taken every day. There are combined forms of reliever and preventer medications that work well for some children and young people.

A definition of good asthma control (NACA, 2015) includes:

- asthma symptoms experienced on less than two days per week and rapidly relieved by bronchodilator medication
- reliever medications needed for less than two days each week
- no limitation on activities
- no disruption to sleep or symptoms on waking.

Asthma management plans are individually tailored guidelines that identify the child or young person’s own goals for treatment and include the tracking of symptom patterns against treatment variations and environmental triggers; advice for managing acute attacks; information about correct medication administration (such as inhaler or spacer...
technique); and about maintaining health (nutrition, immunisation and avoidance of tobacco smoke). Developed in partnership with the child, their family or carers, and health professions, the asthma management plan is a useful tool for continuously monitoring and adjusting treatment to achieve symptom control, increasing health literacy, and reducing future risk of exacerbation or medication side-effects (GINA, 2016).

The most common causes of poor asthma control in children are problems with inhaler technique, inappropriate medication dose or type for the age and stage of development, the inability of the child or family to follow the asthma management plan recommendations, and exposure to as yet unidentified asthma triggers. The asthma management plan needs continuous review as the child grows and begins to take more responsibility for the monitoring and control of their asthma. For Harriet, entry into adolescence, combined with her unstable (sometimes called ‘brittle’) asthma and recent acute episode, gives a clear indication that it is time to review her plan. If the child or young person agrees, it is useful for their general practitioner, school, child-care or sporting club to have copies of their plan. Asthma first aid protocols, ‘how to’ videos and quick reference guides are all freely available from NACA.

**Type 1 diabetes**

*Type 1 diabetes mellitus (T1DM or T1D)* accounts for the majority of childhood cases of diabetes in Australia (sometimes still called juvenile diabetes), and is estimated to account for 10 per cent of all diagnoses of diabetes in this country (AIHW, 2011). Early results from the Australian National Health Survey 2014–15 (ABS, 2015b:14) show a small rise (0.7 per cent) in the number of people with T1D from 2011–12 to 2014–15; however, the incidence (number of new cases) of T1D has remained stable
at around 10–13 cases per 100 000 population for more than a decade (AIHW, 2015a). Categorised as an autoimmune condition, the exact cause of T1D is unknown, but is believed to be the result of an interaction of genetic predisposition and environmental factors (Craig et al., 2011).

As with all nursing practice, an understanding of basic physiology will help you to deliver the best possible care to a child or young person with TID. The pancreas produces a range of enzymes and hormones important for normal digestion and energy regulation. Insulin is produced by beta cells in the pancreas; when beta cells are damaged, insulin is not produced and blood glucose levels become elevated. Glucagon-producing cells also become damaged, leading to a loss of glucagon regulation, even when insulin therapy has commenced. The function of the hormone glucagon is to increase blood sugar when levels become too low.

Type 1 diabetes is currently incurable, and there is no known way to prevent it. Once diagnosed, insulin replacement will be required every day throughout life to control blood sugar levels, unless the child or young person receives a pancreatic transplant. Despite the establishment of a National Diabetes Register for insulin-treated diabetes in 1999, it is still not possible to accurately capture the prevalence of T1D at all ages. However, it is estimated that more than 6000 Australian children aged 0–14 years had T1D in 2013 (AIHW, 2015b). The incidence of T1D increases with age, peaking during early adolescence and coinciding with puberty. In 2014, the peak age of diagnosis was between 10–14 years of age, yielding an incidence rate in this age group of 33 cases per 100 000 (AIHW, 2016). T1D does not discriminate: there are no major differences in incidence at any age between socioeconomic groups, area of residence or remoteness (AIHW, 2016).

The typical presentation of T1D includes a pre-clinical phase, a presentation phase (usually when symptomatic), a partial remission
(known as the ‘honeymoon’ phase), followed by a chronic phase requiring long-term insulin replacement. The presenting symptoms of T1D may include polyuria, polydipsia, hyperventilation, tiredness, confusion and abdominal pain or vomiting; occasionally, T1D is detected incidentally during the pre-clinical phase. Symptoms and presentation may vary and T1D can easily be misdiagnosed as any of a range of childhood illnesses. When metabolic symptoms are mild, T1D may also be difficult to differentiate from type 2 diabetes (T2D), particularly in children and young people with signs of insulin resistance – who are generally overweight or obese. If diagnosis is delayed, severe diabetic ketoacidosis will inevitably occur, requiring urgent hospitalisation for rehydration and insulin infusion.

**Nursing assessment and interventions**

Children and young people presenting with T1D are initially managed in hospital, or within an appropriately resourced ambulatory care setting (Craig et al., 2011). In-patient management is recommended for children under 2 years of age at diagnosis; those who have significant other medical or social problems; those with inadequate support or mental health issues; those living in geographically remote locations; and those children and families for whom English is a second or poorly understood language.

Effective management of T1D aims to balance blood glucose control with insulin treatment in order to keep blood glucose levels within a normal target range to maintain health, normal growth, quality of life and psychological wellbeing (Craig et al., 2011). Poor blood glucose control is associated with both short- and long-term health consequences (AIHW, 2015b). The Australian National Evidence-based Guidelines for Type 1 Diabetes in Children, Adolescents and Adults (Craig et al., 2011) are a
reliable and highly cited source of evidence for the care of children and young people with T1D. While these refer to international guidelines for glycaemic target setting in paediatric age groups (Craig et al., 2011: 52), Diabetes Australia’s recommendations for T1D (see Diabetes Australia website: www.diabetesaustralia.com.au) are currently based on blood glucose targets of 4–6 mmol/L (before meals), as recommended by the American Diabetes Association.

As with all chronic conditions of childhood, regular care by a paediatric endocrinologist, diabetes nurse specialist and multidisciplinary team is important. Clinicians need to be aware that comorbid psychological disorders, inclusive of eating disorders, are relatively common in children and young people with T1D, and there is an association between glycaemic control and some aspects of educational performance and cognitive function. Although estimates vary, between 0.6 and 16 per cent of people with T1D are also likely to develop the related autoimmune disorder coeliac disease, and will need to commence a gluten-free diet (Scaramuzza et al., 2013). Regular monitoring of height and weight, and ongoing nutrition education is important to ensure normal growth, to prevent overweight or obesity, and for symptomatic assessment of coeliac disease, if present. Insulin requirements will change frequently with growth and in response to periods of illness and high activity and during puberty (Craig et al., 2011).

The specialist health-care team works with the child, young person, family and general practitioner to achieve consistent continuity of care in:

- recommending diabetes care and self-management
- maintaining healthy diet and normal growth and development
- balancing food, exercise and insulin dose
• undertaking regular reviews and screening for diabetes complications
• advising on ‘sick day’ management plans
• resourcing teachers, coaches and others
• offering psychological and psychosocial support.

Strategies to improve access to primary health-care services are an important aspect of coordinated care for children and young people living in remote locations. Telemedicine (e-health) and mobile phone text messaging of blood glucose levels, weight and other information are particularly useful adjuncts to self-management for this group.

A number of recent trials have concluded that continuous subcutaneous injection of insulin using an external insulin pump (a small computerised device worn 24 hours a day) has greater potential to minimise hypoglycaemia and maintain longer-term glycaemic control than multiple daily injections using an insulin pen or syringe and needle (Craig et al., 2011). Insulin pumps have the advantage of being programmable to more closely replicate normal patterns of insulin delivery; however, children, young people and their families need to be highly motivated to succeed in using this currently quite complex therapy. For many, the cost and extra engagement with health professionals is simply not worth it. Of the 6000 children aged 0–14 years with T1D considered by the AIHW (2015b) prevalence report, 43 per cent (or two in five) were using an insulin pump. Those using pumps had been diagnosed with T1D for longer and were from higher socioeconomic groups (AIHW, 2015b: 13).

There are many resources for children and young people affected by T1D that are inclusive of siblings and family, including blogs, online fact sheets, links to support groups, and social and fundraising events, but these
do not negate the daily responsibilities of living with T1D. Table 10.2 outlines some internationally agreed mainstays of treatment for T1D; however, research is prolific and regularly contributes new knowledge and recommendations for care.

**Table 10.2** Essential aspects of care for type 1 diabetes

<table>
<thead>
<tr>
<th>Aspect of care</th>
<th>Supportive treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood glucose monitoring</td>
<td>Intermittent capillary testing of blood glucose level (BGL) using a portable meter or continuous glucose-monitoring system (CGMS). Many blood glucose meters now have the ability to download and store results to smartphones.</td>
</tr>
<tr>
<td></td>
<td>A blood test for glycosylated haemoglobin (HbA1c) shows a longer-term picture (10–12 weeks) of blood glucose control.</td>
</tr>
<tr>
<td>Human insulin or insulin analogues (rapid acting)</td>
<td>Intermittent subcutaneous injection or via continuous subcutaneous infusion (insulin pump).</td>
</tr>
</tbody>
</table>

Hypoglycaemia (low blood sugar) is the most common short-term complication of T1D, and can usually be self-managed by ingestion of a fast-acting carbohydrate such as fruit juice, followed by a longer-acting carbohydrate (such as a sandwich) if not resolving. However, around a quarter of people who have had T1D for 10 years or more may have a
reduced awareness of hypoglycaemic symptoms (Craig et al., 2011). Severe hypoglycaemia, with inability to self-manage, is fortunately much less common. Severe hypoglycaemia manifests as loss of coordination or consciousness, slurred speech, confusion or fitting. Severe hypoglycaemia is a medical emergency that requires the administration of glucagon (a hormone that raises blood glucose levels).

Diabetic ketoacidosis (DKA) is also a life-threatening condition, but it is associated with high blood sugar (hyperglycaemia). When cells cannot get enough energy from sugar due to a lack of insulin (even though blood sugar may be quite high), fat and muscle are broken down, producing acids called ketones that build to dangerous levels in the body. Table 10.3 outlines commonly recognised short- and long-term health complications of T1D. Attention to the long-term maintenance of glycaemic control does have the potential to delay or reduce chronic complications such as retinopathy, nephropathy and neuropathy (Craig et al., 2011).

Table 10.3 Common short- and long-term complications of type 1 diabetes

<table>
<thead>
<tr>
<th>Complication</th>
<th>Possible cause or effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypoglycaemia (low blood sugar)</td>
<td>• Too much insulin</td>
</tr>
<tr>
<td></td>
<td>• Missed or delayed meals</td>
</tr>
<tr>
<td></td>
<td>• High activity, exercise or stress</td>
</tr>
<tr>
<td></td>
<td>• Reduced symptomatic awareness</td>
</tr>
</tbody>
</table>

Diabetic ketoacidosis (DKA) due
to high blood sugar

- Insulin dose too low or missed
- Infection or other illness
- Dehydration
- Stress or excitement

Microvascular (longer term)

- Retinopathy
- Nephropathy
- Peripheral neuropathy

Macrovascular (longer term)

- Cardiovascular
- Cerebrovascular
- Peripheral vascular disease

Weight (longer term)

- Overweight or obese
- Metabolic syndrome

**Type 2 diabetes**

Sources for monitoring the national incidence and prevalence of type 2 diabetes mellitus (T2DM or T2D) in younger age groups are only just
being established; however, data from two national data sets have recently been combined to prepare one of the first working papers on this subject (AIHW, 2014). There is evidence to suggest that the incidence of T2D may be increasing among children and young people, partly due to improved monitoring and diagnosis at all ages, and partly to increased levels of physical inactivity, unhealthy diet, overweight and obesity in these age groups. T2D is unlikely to develop in very young children (0–4 years), but has been diagnosed in children as young as 5 years of age (AIHW, 2014).

The characteristics of T2D are the progressive failure of insulin production and the resistance of body tissues to the action of insulin (insulin resistance). Risk factors for T2D are both modifiable and non-modifiable. For example, up to 85 per cent of children and young people diagnosed with T2D in the United States were overweight or obese at diagnosis (AIHW, 2014); therefore, modifiable risks include preventing obesity through a healthy diet, weight loss and exercise, possibly inclusive of bariatric surgical procedures in those over 15 years of age (ADC, 2012). Non-modifiable risk factors for the development of T2D in young people include maternal diabetes, genetic predisposition to insulin resistance and ethnicity. Australia’s Aboriginal and Torres Strait Islander children and young people have a high prevalence of T2D (AIHW, 2014: 2).

As both T1D and T2D can lead to a range of serious long-term health complications involving the blood vessels and nerves, most young people diagnosed with T2D will commence insulin, even though oral glucose-lowering medication is usually the first line of treatment for T2D in adults. Clearly, the younger a person is at diagnosis, the greater is the risk of complications because of longer exposure to the disease. An additional burden on a young person is the stigma of being diagnosed with a disease that more commonly affects individuals who are older and overweight or
obese. Further, similar to those with T1D, there is the responsibility to self-manage this condition for the rest of their life with potential interference in study or work, and possible disability from the associated comorbidities of diabetes – such as vision impairment, vascular, heart, kidney and nerve damage, and associated stress, anxiety or depression.

**Nursing assessment and interventions**

Strategies for the effective management of T2D in children and young people are not as well advanced as they are for adult patients. Some obvious areas of difference in managing the condition in young people include the effect of hormones and puberty on blood glucose levels, compliance with medication and diet, and complex maturational, emotional and psychosocial effects.

With T1D, the aim of treatment is stabilisation of blood glucose within target levels and prevention of short- and long-term health complications. Optimal management is through regular self-monitoring of blood glucose levels and insulin therapy as above, with the involvement of (initially) a paediatric multidisciplinary team with specialist skills in endocrinology, diabetes education, nutrition, social work and psychology. Effective transition to an adult multidisciplinary team is required for lifelong management of the disease, including care during pregnancy and childbirth.

**Congenital, chromosomal and genetic disorders**

*Congenital anomalies* are a major cause of hospitalisation during infancy and childhood in Australia; however, the collation and reporting of data
specific to the experience of children and young people with these conditions is not routine. There is also limited reporting of the major personal, social, community and economic consequences of caring for children and young people with congenital conditions. The Australian Congenital Anomalies Monitoring System (ACAMS) is supported by the AIHW as a register of congenital anomalies or birth defects across all Australian states and territories, with the exception of the Northern Territory. The last report (Abeywardana & Sullivan, 2008) collated data from 2002–03, and noted that hypospadias – a condition characterised by the opening of the urethra on the ventral side of the male penis – is the most commonly reported congenital condition in Australia (Abeywardana & Sullivan, 2008: 92). According to this report, the overall rate of hypospadias, regardless of the severity of the condition, is approximately 23.8 per 10 000 births, or 46.4 per 10 000 male births.

Neural tube defects occur in approximately 4.2 per 10 000 live births, but it is estimated that up to 76 per cent of affected pregnancies may be terminated or die in utero (Abeywardana & Sullivan, 2008: 24). Other congenital anomalies associated with chronic conditions of children and young people include spina bifida, cleft lip or palate, intestinal and cardiac anomalies, and limb-reduction deficits.

Children with chromosomal birth defects or abnormalities are born with either an irregular number of chromosomes or with one or more chromosomes that have an irregular structure, such as a duplication or deletion. Trisomy 21, or Down syndrome, is characterised by minor or major congenital malformations associated with excess chromosomal material (all or part of a third copy) or translocations of chromosome 21. Down syndrome is the second most commonly reported congenital condition in Australian children, occurring more commonly with advancing maternal age and at a rate of 11.1 per 10 000 live births. It is
estimated that approximately 64 per cent of foetuses affected by this chromosomal abnormality are either managed by termination or die in utero, making the actual rate for Trisomy 21 closer to 26.3 per 10 000 pregnancies (Abeywardana & Sullivan, 2008: 140). Other common chromosomal conditions in Australia are Klinefelter syndrome (which affects boys), Turner syndrome (which affects girls), and Prader-Willi and Angelman syndromes.

Single gene defects describe conditions for which defects in a certain (single) gene have been identified as the cause of a disorder. Single gene defects have predictable inheritance patterns and can be classified as recessive, dominant or X-linked. Neurofibromatosis is caused by an autosomal dominant gene defect (only one copy of the changed gene is required to be affected by the disease), with the mild form occurring in one per 2500 to 4000 live births in Australia. Recessive disorders can only occur when both parents are carriers of the recessive gene and the child inherits two copies of the mutated gene. Cystic fibrosis is one of the more common (autosomal recessive) single gene defects and because symptoms affect a range of body systems, paediatric nurses are very likely to encounter children and young people affected by this condition. Other single gene defects cause Huntington disease, phenylketonuria (PKU), sickle cell disease, Tay-Sachs disease, thalassaemia and Duchenne muscular dystrophy (an X-linked condition affecting boys).

**Cystic fibrosis**

*Cystic fibrosis (CF)* is the most common life-limiting autosomal recessive genetic condition in the Australian population, with an incidence of approximately one in every 3630 (or 28 per 100 000) live births (CFA, 2016). On average, one in 25 people of European/Caucasian descent
carries the CF gene (over one million Australians), but most are unaware that they are carriers. The gene responsible for the symptoms of CF, the cystic fibrosis transmembrane regulator (CFTR) protein gene, was discovered in 1989 (Riordan et al., 1989). To be born with CF, both CFTR genes must be affected by a CF-causing mutation. More than 2000 different mutations of the CFTR have now been identified, which partially explains previously observed variances in the symptomatic and geographic presentation of this condition.

As before, a basic understanding of the physiology of CF will help you to deliver the best possible nursing care to a child or young person with this condition. CFTR is a protein that functions as a channel across the membrane of epithelial cells. CFTR controls chloride ion transportation across the cell membrane, thereby controlling the movement of water in and out of the cell. Since water is necessary for the free flow of mucus, the symptoms of CF are largely observed in those organs that rely on lubrication by mucus, including the lungs and gastrointestinal system (intestine, pancreas, gall bladder and liver). Sodium ion transport is also affected. The most common CF mutation in Australia and around the world is a deletion in the CFTR protein called ∆F508 (found in 90 per cent of cases), with the G551D mutation (around 7 per cent of cases) being the second most common (CFA, 2016; ECFS, 2016).

There is good evidence of benefit from early diagnosis and treatment intervention in CF (Dijk et al., 2011) and gene mutation analysis has now been added to the Australian neonatal (blood spot) screening test for CF, significantly increasing the sensitivity and specificity of this test (Massie et al., 2012). More than 60 per cent of new cases of CF presenting in Australia in 2014 were diagnosed by newborn screening (CFA, 2016: 12). Screened (and non-screened) cohorts have been entered into CF registries around the world, with the Australian Cystic Fibrosis Data Registry
(ACFDR) consistently collating information on the demographics, clinical features and outcomes of people with CF in Australia. Neonatal screening has contributed greatly to our understanding of this genetic disorder, and to improving the treatment of respiratory and nutritional symptoms of infants with this condition, but there are likely many other factors contributing to improved survival in CF. These include improvements in coordinated, multidisciplinary CF centre-based care; availability of bacteria-specific antibiotics; improved medications and physiotherapy techniques for chest clearance; maintenance of normal growth through nutritional support and pancreatic enzyme replacement therapy (Bell, Robinson & Fitzgerald, 2008); and organ transplantation (CFA, 2016).

While the survival outlook for children diagnosed with CF was previously bleak, the ACFDR (CFA, 2016) recorded an important demographic milestone in 2016, noting that now more than half of those in the surviving population with CF in Australia are adults. In a recent Australian study, the mean age of death from CF between 1979 and 2005 reportedly increased from an average of 12.2 to 27.9 years for males, and from 14.8 to 25.3 years for females (Reid et al., 2011). The ACFDR (CFA, 2016: 34) reports that the median age of death from CF in 2014 was 27.7 years. While this is clearly an achievement, living into adulthood with a chronic condition like CF introduces many other medical, social and psychological challenges, as discussed in Chapter 4, where we were introduced to Ellen, a 16-year-old young woman with CF (see Case Study 4.6).

Nursing assessment and interventions

While more than half of new cases of CF in Australia will present through neonatal screening, the ACFDR reports that in 2014, other modes of
presentation included respiratory and gastrointestinal symptoms in around 10–14 per cent of infants (CFA, 2016: 12). As more than 80 per cent of infants with CF will be diagnosed before they are 3 months of age, it is likely that early contact with health professionals will focus on establishing diagnosis and initiating preventative treatments as recommended by the Cystic Fibrosis Standards of Care, Australia (Bell, Robinson & Fitzgerald, 2008), outlined in Table 10.4.

**Table 10.4** Establishing treatment in the newly diagnosed infant with cystic fibrosis

<table>
<thead>
<tr>
<th>Access to specialist CF centre or service</th>
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<tbody>
<tr>
<td>• Prompt access to experienced medical, nursing and allied health team for support during diagnostic phase and to establish ongoing care</td>
<td></td>
</tr>
<tr>
<td>• Confirmation of diagnosis by sweat test</td>
<td></td>
</tr>
<tr>
<td>• Assessment of pancreatic function and commencement of enzyme replacement therapy if required</td>
<td></td>
</tr>
<tr>
<td>• Salt, electrolyte and vitamin replacement therapy, especially in hot, humid conditions</td>
<td></td>
</tr>
<tr>
<td>• Establish plan for symptom recognition, preventative management and regular follow-up appointments</td>
<td></td>
</tr>
<tr>
<td>Family support, education and counselling</td>
<td></td>
</tr>
<tr>
<td>• Access to all CF team members for education and support with initial</td>
<td></td>
</tr>
</tbody>
</table>
management of condition

- Establish contact with support organisations and people
- Access to genetic counselling and family genetic testing

There is no cure for CF, so treatment is aimed at managing symptoms to slow organ damage caused by the disease and maintaining normal nutrition for growth. As the CFTR gene impacts fluid transport across exocrine cells, the resulting abnormally thick mucus will lead to varying degrees of blockage of ducts in the bronchi, pancreatic ducts and intestines. Blocked mucus in the lungs traps bacteria and can cause infection. Pancreatic enzymes required for normal digestion can also be blocked in the pancreas, and around 80 per cent of children and young people with CF will require enzyme replacement therapy to help digest their food and maintain normal nutrition (CFA, 2016). The treatment of CF has improved greatly in recent years and, as for all the chronic conditions of children and young people we have reviewed so far, regular attendance at a dedicated CF centre or clinic facilitates specialist care from a multidisciplinary team that includes respiratory physicians, gastroenterologists, physiotherapists, dietitians, psychologists, pharmacists, geneticists, educators, occupational therapists, social workers and paediatric nurses. Following the initial diagnosis, children and young people with CF in Australia can expect to attend an average of four to five clinic visits each year (CFA, 2016).

While mucolytics and oral or inhaled antibiotics are a mainstay of treatment for respiratory symptoms in CF, almost half of all patients attending CF clinics will be admitted to hospital at least once each year for
intravenous antibiotic treatment of a respiratory infection or for a range of other complications associated with their disease (CFA, 2016). These may include nasal surgery, procedures for more permanent intravenous access devices, insertion of nasogastric or gastrostomy tubes for supplemental feeding or treatment of intestinal obstruction. Around 10–15 per cent of older children and adults will complete their intravenous antibiotic treatment for acute respiratory infections at home (once intravenous access and dosages are established), but younger children are also increasingly being managed by parents or carers at home, or through Hospital in the Home (HITH) and similar services. While *Staphylococcus aureus* is the most commonly identified organism causing respiratory infections in younger children with CF, children older than 12 years are more likely to be colonised with various species and forms of *Pseudomonas* (CFA, 2016: 16). *Haemophilus influenza* infection is also common in younger children, especially those 2–5 years of age.

The medical complications of CF, including reduced lung function, increase with age (see Table 10.5). More than 20 per cent of adult patients with CF (over 18 years of age) will develop insulin-dependent diabetes and abnormal liver function tests, and almost half will have gastro-oesophageal reflux (CFA, 2016). More than 40 per cent of those aged 30 years and over are likely to have osteoporosis or osteopenia due to nutritional comorbidities and long-term medication use (CFA, 2016: 18).

**Table 10.5** System complications of cystic fibrosis

<table>
<thead>
<tr>
<th>System</th>
<th>Complication or effect of disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pulmonary</td>
<td>• Infection</td>
</tr>
<tr>
<td></td>
<td>• Haemoptysis</td>
</tr>
</tbody>
</table>
Similar to other chronic conditions described in this section, children and young people with CF should have a plan of management for symptoms, acute infections, exercise, nutrition and medication. Young people should be involved early in self-care and treatment decisions, and in preferences for transition to adult services and for end-of-life care. The management plan should preferably be in a form that can be shared with family, carers, schools and medical teams.
The parents of children and young people with CF carry a significant burden of care every day of their child’s life. In addition to the normal routines of raising and educating a child or young person, and caring for their developmental and emotional health, there are daily responsibilities for physiotherapy, including inhalations and airway clearance of mucous, attention to nutrition and enzyme replacement therapy, and maximising compliance with a range of daily medications and exercise. Apart from treatment of normal childhood illnesses and injuries, clinic visits and hospitalisations in children and young people with CF account for significant periods of time away from home. This has many sibling, family, relationship and financial implications, especially for those living in rural or remote locations.

Children and young people with CF are expected to adhere to a range of treatments and preventative therapies, including:

- routine clinic visits and physical examinations
- annual review including chest x-ray, blood tests, nutritional and gastrointestinal assessment, spirometry (from 5 years of age) and sputum sample
- oral antibiotic therapy prophylactically, continuously or as needed
- pancreatic enzyme replacement
- nutritional and vitamin supplementation
- inhalations (bronchodilators, antibiotics and steroids)
- salt tablets
- oxygen therapy (as needed).

Trials of new drug therapies aimed at enhancing the function of the CFTR protein (the underlying cause of the disease) are currently underway.
in North America and parts of Europe, but these drugs are not currently available in Australia. Organ transplantation is an end-stage treatment for CF. In 2014, the Australian Cystic Fibrosis Data Registry reported 35 Australian patients had received a transplanted organ in that year. Bilateral lung transplant was the most common procedure (97 per cent), but only one recipient was in the 12–17 years age group (CFA, 2016); another patient had undergone a liver transplant.

**Reflection points 10.2**

- Chronic medical and genetic conditions require a daily, lifelong commitment to care. Investigate the research literature for studies on medication compliance in young people with chronic conditions as a way of informing your nursing care.

- The National Health and Medical Research Council (NHMRC) recently released a statement on DNA genetic testing in the Australian context. Genetic testing continues to present a range of challenges for health professionals and some tests are available for purchase via the internet (direct to consumer, or DTC). Think about some of the positive and negative outcomes of DTC testing and discuss how you might discuss these with a family seeking your advice.

- A recent survey of people with CF and parents of children with CF (n=62) identified that 44 per cent would like more options for Hospital in the Home (HITH) services and 23 per cent would like more options for GP care (ACI, 2015). Interestingly, 19 per cent identified that they would like more options for care via
Transition to adult care

The range of chronic medical, metabolic and genetic conditions affecting children and young people is broad and, as we have seen, many conditions will persist from childhood through adolescence and into adulthood. Individuals who experience these conditions and who survive to reach adulthood will face the important developmental task of transitioning to adult care. The process of transition has been identified for some time as the ‘purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centred to adult orientated health care system’ (Bloom et al., 2012: 213; Blum et al., 1993: 570).

Transitioning from paediatric to adult care is a complex process that often takes several years. There is no ‘right’ time for transition, but setting a target transfer age helps the young person and their family, and the multidisciplinary health-care team, to plan and prepare for the future. Transition will usually commence between the ages of 16 and 18 years, or when a young person leaves secondary school (Jermyn, 2013), but this will depend upon the service organisations, the availability of their resources, the maturity and knowledge of the individual with the chronic condition, the level of family support they have, the nature and severity of their condition, the country in which care is being delivered and their personal preferences (Garvey et al., 2012; Jermyn, 2013; McInally, 2013; Tuchman & Schwartz, 2013; Wisk et al., 2015).
The successful transition of young adults to adult services also requires attention to their physical, emotional and psychosocial needs (for example, education, employment, finances, housing, family relationships, access to medication, safety, driving, travel, intimacy, sexual and reproductive health, lifestyle and parenting). A transition process that focuses solely on the illness and its treatment is unlikely to meet the needs of the young person (ACI, 2014; Fegran et al., 2014; Jermyn, 2013; Porter et al., 2014). It is also important to remember that the timing of most transition experiences will fall within a developmental stage in young people that is often associated with rebellion, non-compliance and sometimes frustration and anger, as the young person tries to make sense of the world and their place within it.

**Important considerations during transition**

Let’s return to the situation of Ellen (Case Study 4.6 in Chapter 4), a 16-year-old young woman with CF. Ellen had graduated from the children’s hospital ‘transitional care program’, but naturally held some reservations about moving to the adult hospital.

### Case study 10.2

**Ellen**

Ellen is a 16-year-old young woman with CF. She has now transitioned to the adult CF clinic. Ellen was late for her first appointment because her mum couldn’t work out where to park and Ellen had to walk a long way to the clinic, arriving hot, tired, breathless and coughing. Ellen did not recognise any of the other patients in the waiting room, and some of them looked really sick.
There was not a single staff member she knew. She went to the coffee shop, but she missed seeing her friend Sharon behind the service counter. By the time her mother arrived, Ellen had been taken in to see the registrar, who was in the process of asking her to recite her entire medical and surgical history from when she was a baby. Ellen said, ‘Don’t you have my notes from the other hospital? Can’t you just read them?’ The registrar then asked Ellen’s mum to leave the room while she undertook a clinical examination. Ellen decided that she did not want to share any of her previous history with this person – if this new doctor didn’t care enough to read her notes and the referral letter from her pediatrician, why should she waste her time?

The move from paediatric to adult health-care services is characterised by a number of assumptions that are often not made explicit. Of particular importance is the assumption that the client will take a greater level of individual responsibility for managing their care in an adult service (Begley, 2013; Chessir et al., 2013; Fegran et al., 2014). Parents or caregivers who may previously have played a significant role in decision-making are designated to a more peripheral role (Jermyn, 2013), their deep contextual and historical knowledge lost. Some young people find this new responsibility for decision-making intimidating or overwhelming – especially if they have not been prepared adequately. Some parents also find it difficult to disengage from a role they may have held for a long time. Other assumptions include the giving of support, orientation and advice to help the young person ‘way-find’ in their new environment, to use different technologies for appointment and results
notifications, and to manage personal electronic health records (APA, 
2009; Begley, 2013).

The movement from paediatric to adult services also requires getting used to a new health-care team and negotiating new relationships. The young person moves from specialist paediatric service providers (for instance, a paediatric endocrinologist, paediatric nurses, educators and dietitians) to adult service providers who may be used to delivering services to much older patients and who are practising within a different organisational context, and possibly in a different location. The young person (either in consultation with their paediatric team or independently) will need to find a suitable adult health-care provider, and work towards establishing rapport and understanding with a new health-care team that will rarely have the same extensive understanding of their previous history and may include new members such as genetic counsellors, surgeons or obstetricians (McInally, 2013; Oswald et al., 2013).

Another important challenge associated with the transition to adult care is the fact that this period will likely coincide with a number of other ‘stage-of-life’ decisions. On reaching late adolescence, young people may decide to move out of the family home, go to university, start full-time work, pursue intimate relationships, travel or consider starting a family. While these aspirations are often taken for granted, the kinds of support available for the continuation of comprehensive care to a young person with a chronic condition will have a profound impact on the outcomes they can realistically expect to achieve (AIHW, 2014).

**Successful transition**

A successful transition is promoted by health-care providers who listen to, and who are sensitive and supportive of, the needs of the transitioning
clients (Okumura et al., 2014). In their study of young people with T1D, Ritholz and colleagues (2014) found that the transition process often raises a variety of emotions, including sadness and reluctance to separate from providers who have often been a part of the young person’s life for a significant period of time. Consequently, it is important for adult providers to be aware of and sensitive to these emotions.

It is also recognised that health education, policy and research have failed to keep pace with rapid growth in the numbers of young people with often complex chronic conditions moving to adult care (Sharma et al., 2014). Adult health-care providers are often unaware that young people who are moving from a paediatric to an adult service will have insights into their own condition and needs that are different from those of adult clients who have not previously been involved with health-care systems (Betz et al., 2013). Contrast the experience of Ellen (Case Study 10.2), for example, with that of a young adult presenting to an adult respiratory clinic for the first time. Throughout the transition process, young people may experience feelings of not belonging and of being redundant (Fegran et al., 2014). Adult health-care professionals need to understand, respect and actively acknowledge the years of personal insight and comprehensive knowledge that chronically ill young people have developed about their own bodies and their own disease.

Good preparation is another important factor in ensuring a successful transition to adult care (Jermyn, 2013). Talking about transition should ideally commence early in the teenage years (around 14 years of age), progressing over the next few years with a view to moving care completely to adult providers by 16–18 years of age (ACI, 2014). Throughout, there must be active consultation between the young person, their family and both the paediatric and adult care facilities. Many health-care facilities have introduced formal transition programs to aid movement from
paediatric to adult care, although there is a wide discrepancy in their availability and success across different health conditions, and across states and countries (McInally, 2013; Okumura et al., 2014). There is evidence that the inclusion of a dedicated local transition facilitator, with responsibility for the coordination of the transition and the people involved, has a positive impact (ACI, 2014). Advance planning and encouraging young people to gradually take on more of the responsibility for their health-care decision-making can also make the transition process smoother (Hilliard et al., 2014). Similarly, good relationships and clear communication between the paediatric, transition and adult health-care teams are vital (Kaufmann Rauen et al., 2013).

Standardising the content of transition preparation programs within a paediatric service improves program efficiency. Similarly, introducing transition-oriented clinics for late adolescents and young adults can also be effective in allaying common transition-related fears and establishing the young person’s preferences for adult care (Hilliard et al., 2014). A carefully planned and well-executed transition process, with regular evaluations and reviews, will assist young people to continue their stage-of-life development and maintain their health as they move to an adult care setting (Jermyn, 2013).

Factors known to contribute to the successful transition of young people with chronic conditions to adult care, and therefore useful to include in transition programs, are:

- clear communication between paediatric and adult health-care providers at the transitioning institutions
- early planning of the transition process over a period of time (years rather than months)
• involving all stakeholders including the current main carer, GP and/or family in the process

• gradually encouraging more involvement of young person in health-care decision-making

• a local transition case manager or facilitator for each individual

• transition clinics (hybridisation of paediatric and adult service) and introduction to peers who have successfully made the transition

• access to practical and online resources (checklists, maps, parking, names, contact details, who does what, social media, apps, chat rooms and blogs)

• flexibility and consideration of timing of other life events (such as final year at school)

• maintaining contact after the transition.

Despite best intentions, the planning process for transitioning young people with a chronic condition to adult care is still often neglected (Fegran et al., 2014; Garvey et al., 2012; McManus et al., 2013). Service gaps of six months or more are commonly reported between young people leaving the paediatric provider and establishing consistent relationships with adult care providers (Garvey et al., 2012), especially when young people and their families are left to locate the adult service themselves (Fegran et al., 2014). Ineffective transition and loss of young people to follow-up can be responsible for unnecessary morbidity, excess mortality, preventable emergency room attendances and expensive investigations. The flow-on effects for the young person are a potential loss of earnings, reduction in reproductive potential and impact on relationships. In one study of young people with T1D, fewer than half of the respondents
reported receiving a recommendation for an adult provider, and fewer than 15 per cent reported having a transition preparation visit or receiving written transition materials (Garvey et al., 2012).

The health needs of young people with a chronic condition are multifaceted, and exist within a microsystem within which communication, psycho-social support and the models of transition, clinical expertise and resources available from both adult and paediatric environments will directly affect ongoing health and care. The scarcity of health-care professionals in the adult care sector with specific experience in childhood chronic conditions, and problems finding an adult specialist, are on their own sufficiently understandable reasons for young people’s dissatisfaction with transitioning to adult care (Hilliard et al., 2014; Oswald et al., 2013). Anticipated future needs include the establishment of specialist facilities and resources for appropriate transitioning, education and training for health-care professionals in the prevention and treatment of acquired complications associated with improved survival in previously life-limiting paediatric conditions, and developing appropriate models of care for young adults seeking lifelong physical and emotional support from health-care teams.

Reflection points 10.3

- In your work as a paediatric nurse, how have you contributed to preparing young people with chronic conditions for their transition to adult health care?
- Do you know whether a transition to an adult health-care program is part of the service offered by the organisation for
which you work? If so, what defining features of the program make it a success? How is success of the program measured?

- Parents and carers play a vital role in planning for transition. What three things can you suggest to parents or carers to prepare their young person with a chronic condition for this process? (Hint: encourage the young person to keep a journal and write down questions.)

Summary

- Chronic conditions are those that cause a persistent, long-term (more than six months) functional limitation or health burden that requires care or services beyond those regarded as routine. More than 35 per cent of children and young people in Australia have at least one long-term chronic condition.

- Asthma, diabetes and cancer are among the most common chronic medical conditions affecting children in Australia. Collectively, these three conditions account for almost 20 per cent of the burden of disease among children aged 0–14 years. There are many other congenital and acquired conditions that significantly impact on the growth, ability and wellbeing of Australian children and young people, causing chronic ill-health or disability.

- Asthma is the most common long-term chronic condition, affecting almost 10 per cent of all Australian children aged 0–14 years. It is likely that, rather than being a single condition, asthma represents a spectrum of conditions with different pathophysiology.
While childhood asthma is most often associated with hypersensitivity to allergens, the environment, lifestyle, maternal nutrition and weight, and genetic factors are also thought to play a part in its development.

A diagnosis of asthma may place considerable burden on the child and their family, but in most cases asthma can be managed effectively with preventer treatment, the avoidance or control of trigger factors, appropriate medication and an individualised asthma management plan.

Type 1 diabetes (T1D) is an autoimmune condition affecting approximately one in every 300 children and young people in Australia, or one in 720 children aged 0–14 years. Incidence increases with age, peaking during early adolescence. It is likely to be caused by an interaction of genetic and environmental factors. Damage to the insulin-producing (beta cells) of the pancreas prevents the control of blood glucose, with elevated blood glucose levels the cause of short- and longer-term health consequences.

The incidence of type 2 diabetes (T2D) may be increasing among children and young people due to increased levels of physical inactivity, poor nutrition, and overweight and obesity.

The main aim of management of both T1D and T2D is the regular monitoring of blood glucose to achieve control of blood glucose levels within the target range using insulin. Insulin can be administered intermittently by syringe and needle, or by an insulin pen; however, computerised 24-hour insulin pumps are gaining in popularity. Long-term glycaemic control will optimise the
prognosis of the disease and maintain quality of life, normal
growth and psychological wellbeing.

- Common congenital conditions include hypospadias, neural tube
defects such as spina bifida, cleft lip or palate, intestinal atresia or
stenosis, and limb-reduction deficits. The most common
chromosomal birth defect is Trisomy 21, or Down syndrome.

- Cystic fibrosis (CF) is the most common life-limiting autosomal
recessive genetic condition in Australia, with an incidence of
approximately one in every 3600 live births. More than 2000
different mutations of the gene responsible for the symptoms of CF
have now been identified. The spectrum of illness is characterised
by lung and gastrointestinal complications, but there is great
variance in symptoms and the systems affected.

- Neonatal screening has enabled the commencement of earlier
treatment for the respiratory and nutritional symptoms of CF.
Concurrent improvements in coordinated, multidisciplinary CF
centre-based care, availability of bacteria-specific antibiotics,
improved medication and physiotherapy techniques for chest
clearance and maintenance of normal growth through nutritional
support and pancreatic enzyme-replacement therapy have all
contributed to improved survival rates.

- An increasing number of children with chronic physical and
medical conditions who survive to adulthood will need to make a
transition to adult care at some time during their adolescence or
early adulthood. As many children with chronic congenital and
genetic conditions previously died before reaching adulthood, few
adult physicians have been trained to care for the adult consequences of these disorders.

- There is no ‘right’ time for transition, but setting a target transfer age is known to assist planning and preparation. The transition process often raises a variety of emotions for the young person and their family, and it is important for adult care providers to be aware of these emotions. Clear communication, early planning and the involvement of all stakeholders are features of successful transition programs.

- There is limited reporting of the personal, emotional, social, community and economic costs of chronic conditions affecting Australian children and young people.

- The availability and accessibility of evidence-based recommendations for the care of children and young people with chronic conditions are variable. However, the children and young people living with these conditions, and their parents and carers, have intimate daily insight into what does and does not work for them. The nursing care of chronically ill children and young people therefore relies on a sophisticated and informed integration of the best available evidence from research, and careful listening and learning from the experience and needs of the whole family.

**Learning activities**

**10.1** Using the resource link in the Further Reading section below, consult the *Australian Asthma Handbook* to write an asthma management plan for Joel. Joel is 6 years old and has been
hospitalised twice for acute asthma. His mother has remarried recently, and he has two siblings, aged 6 months and 2 1/2 years.

10.2 Smartphone applications, or ‘apps’, are being developed to greater levels of sophistication every day. Undertake an internet search of smartphone apps for managing T1D and T2D, and discuss what you find. Do you think smartphone apps make managing diabetes easier for children and young people? Is there any potential for harm?

10.3 Undertake an investigation at your workplace and report on the processes, plans and resources available for young people with chronic conditions transitioning to adult health care. If you work in an adult hospital, what processes, plans or resources are in place for the young person transitioning to the adult health-care environment?

Further reading

Asthma


- The International Study of Asthma and Allergies in Childhood (ISAAC) was the largest worldwide collaborative research project ever undertaken, involving more than 100 countries and nearly two million children with asthma. See [http://isaac.auckland.ac.nz](http://isaac.auckland.ac.nz). The
program has now finished and work continues under the auspices of the Global Asthma Network (see below).

- The Global Asthma Network was established in 2012 to improve asthma care globally, with a focus on low- and middle-income countries, through enhanced surveillance, research collaboration, capacity-building and access to quality-assured essential medicines. See www.globalasthmanetwork.org.

- The Global Initiative for Asthma (GINA) works with health-care professionals and public health officials around the world to reduce asthma prevalence, morbidity and mortality. See www.ginasthma.org.

**Diabetes**

- The National Evidence-based Clinical Care Guidelines for Type 1 Diabetes for Children, Adolescents and Adults were developed by the Australasian Paediatric Endocrine Group and the Australian Diabetes Society. They remain an authoritative source of information for people with T1D and health professionals. See www.nhmrc.gov.au/guidelines/publications/ext4.

- Diabetes Australia was established as a national body in 1984 and is dedicated to reducing the impact of all types of diabetes through the dissemination of information and research in partnership with people with (or at risk of diabetes) and all health professionals. See www.diabetesaustralia.com.au.

- Diabetes Australia hosts a website and Facebook page called MyD for young people aged between 16 and 25 years to support
information and discussion about school, relationships, going out etc. See http://myd.ndss.com.au.

- The Juvenile Diabetes Research Foundation (JDRF) is a major fundraising body for T1D research. With staff in seven countries, including Australia, the JDRF is also an information resource for supporting and networking young people, siblings and families affected by T1D. See www.jdrf.org.au/home.

- as1diabetes is a website for children and teens with T1D. See http://as1diabetes.com.au.

Cystic fibrosis

- A consensus statement on Standards of Care for Cystic Fibrosis has been collaboratively developed by the Australia and New Zealand (ANZ) Cystic Fibrosis Nurses Group, Cystic Fibrosis Australia and the Thoracic Society of Australia and New Zealand. This is based on standards of care first developed by Bell et al. (2008). See www.thoracic.org.au/journal-publishing/command/download_file/id/16/filename/ANZ_NURSING_SOC_CF_2015.pdf.

- Cystic fibrosis support service organisations exist in every major jurisdiction of Australia, supporting research and lobbying for better health and wellbeing outcomes for those living with CF. See www.cysticfibrosis.org.au.

Transition to adult care
• The New South Wales Agency for Clinical Innovation (ACI) Transition Care Network is one example of a state-based organisation aiming to improve the continuity of care for young people with chronic health problems as they move from paediatric to adult health services by establishing key principles. See www.aci.health.nsw.gov.au/__data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf.

• The ACI also offers access to a range of online resources for young people with chronic conditions who may be transitioning to adult care. See www.aci.health.nsw.gov.au/resources/transition-care.

• Many other transition resources are available, including:
  • Victoria: See www.rch.org.au/kidsinfo/fact_sheets/Transition_to_adult_health_services.

References


Blum, RWM et al. 1993, Transition from child-centered to adult-health care systems for adolescents with chronic conditions, Journal of Adolescent Health, 14, pp. 570–6.


Dijk, F, McKay, K, Barzi, F, Gaskin, K & Fitzgerald, D 2011, Improved survival in cystic fibrosis patients diagnosed by newborn screening compared to a historical cohort from the same centre, Archives of Disease in Childhood, 96(12), pp. 1118 –23.


European Cystic Fibrosis Society (ECFS) 2016, ECFS Patient Registry: Annual data report 2013, ECFS, Copenhagen, viewed 30 September 2016,


**Chronic condition** – Any ongoing physical or mental impairment that causes a persistent functional limitation (or health burden), or necessitates the use of a service or care beyond that regarded as routine. The ABS (2009) defines a chronic condition as one that has lasted, or will last, for six months or more.

**Asthma** – A chronic lung disease characterised by the presence of both excessive variation in lung function and respiratory symptoms such as wheeze, shortness of breath, cough and chest tightness. Where age or
level of development precludes formal lung function testing, diagnosis is based on the presence of respiratory symptoms alone.

**Type 1 Diabetes (T1D)** – A lifelong autoimmune disease that develops when the immune system is triggered to damage the insulin-producing cells of the pancreas, preventing the normal production of insulin and leading to a rise in blood sugar levels. Diabetes is very uncommon in infants under 1 year of age. Type 1 diabetes typically presents during childhood and adolescence, but can be diagnosed at any age.

**Congenital anomalies (also known as birth defects)** – Health problems or physical anomalies that are present at birth and may result in long-term disability, morbidity or death

**A chromosomal birth defect** – A birth defect caused by an alteration in the number or structure of chromosomes (extra copies or missing copies of specific chromosomes), or having chromosomes with missing or extra pieces. Chromosomes are the genetic structure of a cell that carries DNA.

**Gene defects** – Mutations or alterations to chromosomes (the genetic structure of a cell that carries DNA), causing abnormalities in the genome. These defects cause genetic disorders that are present from birth (congenital).

**Cystic fibrosis (CF)** – Caused by mutations of the cystic fibrosis transmembrane conductance regulator (CFTR) protein gene, resulting in abnormal regulation of chloride and sodium transport at the surface of epithelial cells. This results in a multisystem disease characterised by lung and digestive complications.

**Transition to adult care** – The purposeful and planned movement of the care of adolescents and young people with chronic conditions from a child-centred to an adult-oriented health-care system.
Evidence-based care of children with complex medical needs

Nicola Brown

Learning objectives

In this chapter you will:

- Develop your understanding of evidence-based nursing assessments and interventions used in the care of infants, children and young people with complex medical needs
- Explore causes of complex medical health problems in children and young people
- Appreciate the critical role of families in the care of children with complex medical needs
- Consider resources and services available to families of children and young people with complex medical needs
Introduction

Children with complex medical needs and their families are important and frequent consumers of paediatric health-care services (Burns et al., 2011); however, their needs are not always met (Noyes et al., 2014). Most children with complex medical care needs are cared for at home, with parents primarily responsible for their day-to-day care, often with the support of ambulatory and outpatient services. Depending on the nature of the child’s condition, they may require frequent admission to hospital, psychosocial and socioeconomic support, and resources to maintain health and enable participation in school and other activities of daily living (Burns et al., 2011). The care that parents may be required to provide at home is likely to include procedural care – tasks such as suctioning or medication administration, and physical care such as manual handling, feeding and toileting (Rehm, 2013).

Children and young people who are dependent on medical technology have a higher risk of severe acute illness and are more likely to require admission to an intensive-care unit (Burns et al., 2011; Rehm, 2013). Furthermore, some illnesses may be life-limiting, resulting in premature death in childhood, adolescence or early adulthood. Some children, young people and their families may require palliative care services towards the end of their illness.

It can be difficult to determine when a child can be defined as having complex medical needs (Cohen et al., 2011). What one family finds complex, another family may adapt to more easily. One child with a particular condition may have less severity and more function than another child with the same or a similar condition. Furthermore, the discussion around the care of children with complex medical needs has often used
different terms for similar things – care that is ‘medically complex’, or children who are ‘technology dependent’ or ‘medically frail’.

In this chapter, we will explore some of the causes of complex medical needs in children and young people, and discuss related nursing care and interventions. The important and central role of parents, caregivers and families in the care of children with complex needs will also be considered.

Types of conditions associated with complex medical needs

Case study 11.1

Max and Ahmed
Max and Ahmed are new friends – 6-year-old boys who have recently started school. Each boy has complex medical needs. The school that Max and Ahmed attend is a school for children with high-support needs, with teachers who specialise in the education of children with special needs and additional support staff to assist with the care needs of the children.

Max has a rare protein metabolism condition, and requires feeding with a specialised formula via a gastrostomy button. In early infancy Max began to have seizures, and in later infancy his parents noticed that he was not developing as quickly as his older siblings had done. He was slower to sit, crawl and walk. At 6 years of age, Max has difficulty standing and walking, and has begun to use a walker to assist with mobility. Jo, Max’s mother, is his full-
time carer, and has been a single mother since Theo, Max’s dad, left. Theo has had little subsequent contact with the family.

Ahmed has cerebral palsy. Ahmed was born prematurely at 32 weeks and required admission to a special care nursery. One of the earliest indicators that Ahmed may have had a physical disability was identified by the child and family health nurse, when Ahmed still had problems with head control at 4 months. Now Ahmed uses a wheelchair for mobility, as he has a significant motor impairment due to bilateral spastic quadriplegia. The level of motor impairment means that Ahmed needs considerable physical care, including urinary catheterisation, gastrostomy feeding, transferring and hygiene care. Ahmed has difficulties communicating, and is using a picture board to assist with this. Ahmed lives at home with his parents, Rameen and Aamil, grandparents and two older siblings. His mother and grandmother are his main carers.

Both boys have required admissions to hospital for acute illness in the past. Most recently, Max suffered a fall during a seizure, and sustained a mild concussion when his head hit the kerb. Ahmed has had admissions to hospital for management of respiratory distress due to pneumonia after upper respiratory tract infections.

Diseases that might result in a child having complex medical needs are generally rare; however, the range of diseases defined as ‘rare’ is vast. There are approximately 8000 rare diseases, which affect 6–10 per cent of the population (Zurynski et al., 2008), and these rare disorders may be evident at birth or may emerge during childhood. Children with such diseases may have mild to profound disability, and may have complex
medical needs. It is beyond the scope of this chapter to explore all conditions that might require a child and family to receive complex medical care. Instead, some examples are provided to highlight the more ‘common’ of the ‘rare’ conditions.

Cerebral palsy (CP) is the most common physical disability in childhood, with a prevalence of 2.1 children with CP per 1000 live births (Australian Cerebral Palsy Register Group, 2013). Cerebral palsy is an umbrella term for non-progressive but often changing motor impairment that occurs before or soon after birth (Eunson, 2012). For the majority of children, the brain injury associated with CP is most likely to have occurred during prenatal and perinatal development (Australian Cerebral Palsy Register Group, 2013; Eunson, 2012). No two children or young people with CP are the same. CP can impact on an individual’s physical or intellectual function, activities of daily living and participation in community life (Novak et al., 2013).

As the standard of antenatal and perinatal care has improved significantly over recent decades, it was anticipated that the prevalence of cerebral palsy might decline (Mutch et al., 1992). However, the survival rates of children with more severe types of CP have improved as medical interventions for children born prematurely or disabled have also improved (Eunson, 2012). Current risk factors associated with CP include prematurity, low weight for gestational age, multiple pregnancy and maternal genitourinary infections (Australian Cerebral Palsy Register Group, 2013; Eunson, 2012). The majority of children (including Ahmed) have spasticity (86.6 per cent), and may have other impairments in addition to motor impairment, including epilepsy or intellectual, speech, visual or hearing problems (Australian Cerebral Palsy Register Group, 2013).
Case study 11.2

Caleb

Caleb is a boy, aged 10 years, attending a mainstream public primary school with support from a teacher’s aide.

Caleb was diagnosed with Duchenne muscular dystrophy at 4 years of age. Caleb’s parents had noticed that he took longer to start walking than other children, and at age 4, Caleb could not run well, jump or ride a tricycle. As his dystrophy progressed, Caleb needed to start wearing orthotic braces and began using a motor scooter at school and home. At age 10, Caleb is using a wheelchair to mobilise, but can still stand and weight-bear for short periods, transferring himself with support from chair to bed. He is able to feed himself, and can write and communicate independently. Caleb lives with his parents in a regional town, and the family often has to travel to the city for outpatient treatment at a tertiary-level referral paediatric hospital. The paediatric hospital employs a clinical nurse consultant (CNC) who specialises in children with degenerative conditions. The CNC is an important health-care professional who works in collaboration with the specialist medical team, and the local general practitioner, physiotherapy, occupational therapist and community nursing services in Caleb’s town, and often helps these local health-care professionals to support the family while at home.

Caleb’s parents have decided not to have any more children. They do not wish to risk having another child with muscular dystrophy and want to devote their efforts to caring for Caleb.
Muscular dystrophies are a group of neuromuscular genetic disorders that result in the progressive deterioration of muscle strength and function – another significant cause of physical disability in children and young people. The most serious impacts of this deterioration include diminished respiratory function and immobility (Wang et al., 2010). Most forms occur in children, although some children are not diagnosed until later in life.

Detection and diagnosis of muscular dystrophy can take some time. Usually, parents detect some delay in motor milestones and seek advice during the toddler and preschool years. A combination of clinical signs such as motor delay, serum creatinine kinase, muscle biopsy and genetic screening are used to determine the presence and type of dystrophy (Mercuri & Muntoni, 2013).

The most common form of muscular dystrophy in children is Duchenne muscular dystrophy, an X-linked recessive gene affecting male children like Caleb. Duchenne dystrophy is a life-limiting condition; however, survival into early adulthood has improved with increasing access to mechanical ventilation and use of antibiotics to treat respiratory infections (Mercuri & Muntoni, 2013). As a result, the number of adolescents with Duchenne dystrophy who require support during transition from paediatric to adult services has increased. Longer survival time is associated with increased likelihood of cardiac muscle involvement. Severe ventricular arrhythmia may eventuate and sudden death may be the first indication of this (Mercuri & Muntoni, 2013; Wang et al., 2010).

There are many different types of metabolic conditions, some of which result in developmental disability and may also require specialist care and alternative nutrition. Many of these conditions are detected soon after birth through the newborn screening program (Wilcken, 2010). All
infants born in Australia have newborn screening: a heel-prick blood sample taken and tested for the presence of a number of metabolic and genetic conditions, including inborn errors of metabolism such as phenylketonuria (PKU), hypothyroidism and CF (Royal Australasian College of Physicians, 2015). For some children, like Max, the metabolic condition may not be detected until after birth. Metabolic and genetic conditions may be detected by parents and health-care professionals when there are concerns about delays in development or regressed development, or idiopathic seizures.

Some children may have complex, chronic respiratory conditions, often associated with premature birth or respiratory complications in the neonatal period. Examples include chronic neonatal lung disease or subglottic stenosis. The impact of these respiratory conditions may lessen as the child develops and the respiratory tract becomes larger. Depending on the nature of the condition, these children may require an artificial airway (usually a tracheostomy) and/or oxygen therapy in the early years of life.

### Case study 11.3

**Tobias**

Tobias is a 4-month-old boy, born to Karen and Zane. Tobias is their first child, and was born with Down syndrome and an atrioventricular septal defect. Karen and Zane knew before Tobias was born that he had Down syndrome and a heart problem, as these had been detected as part of prenatal screening.

Tobias was born by caesarean section at 39 weeks, and needed admission to the intensive care unit with initial breathing difficulties. Once these settled, Tobias was transferred to the
special care nursery. Tobias had difficulty feeding as he became easily tired and did not have a strong suck, and therefore needed nasogastric feeding. Prior to discharge, Karen and Zane learned how to prepare and administer nasogastric feeds, and prepare and administer Tobias’s cardiac medications; they also practised inserting a nasogastric tube under the supervision of the nurses. Karen and Zane will need to bring Tobias to the outpatient department regularly to see the cardiac specialists, and plan for Tobias’s heart surgery to correct his heart defect.

**Down syndrome**

**Down syndrome**, a chromosomal disorder of chromosome 21, is one of the more common chromosomal disorders. Older women and other women with heightened risk for having a child with Down syndrome are offered initial screening in the first trimester, and may elect to terminate the pregnancy if the risk of the syndrome is high. Some women and their families decide to continue, and give birth to a child with Down syndrome.

**Characteristics of Down syndrome**

Babies and children with Down syndrome have a distinct physical appearance due to specific physical characteristics of the disorder. Physical characteristics include:

- hypotonia (floppy, relaxed muscle tone)
- laxity of the joints, simian line (single deep crease across the palm of the hand)
Children will have some degree of intellectual disability with considerable individual variation, ranging from mild to profound intellectual disability. Children with Down syndrome also have a significantly higher likelihood of other complex illnesses and problems, including congenital heart defects, leukaemia, atlantoaxial instability, growth delay, thyroid dysfunction, ophthalmic and ear, nose and throat conditions. However, not all children will have all or any of these conditions (Kyle, 2012).

Like Tobias, infants born with Down syndrome often have difficulty feeding. This is due to the hypotonia associated with Down syndrome, which means the infant is less able to latch to a teat or nipple, and may lack a strong suck. When the infant has a cardiac condition as well, they tire more easily during feeding (Kyle, 2012). For these reasons, Tobias has been unable to consume the amount of infant formula he needs, so the decision was made to use enteral feeding via a nasogastric tube. Once Tobias has his heart problem corrected, he may tolerate oral feeding better.
medical needs

In most situations, children with complex medical needs are ultimately cared for by parents and family members at home. However, in many cases infants and children are cared for a prolonged period of time in hospital prior to discharge into the care of their family (Elias, Murphy & Council on Children with Disabilities, 2012; Noyes et al., 2014). Prior to discharge, parents and caregivers often need to learn new skills and gain new knowledge in order to care for their child at home, and integrate the care into the day-to-day life of the family.

Children are now frequently sent home with the ongoing need for interventions such as oxygen, tracheostomies, ventilation, enteral feeding, care of intravenous devices and complex medication regimes (to name just a few) that previously would have occurred in hospital (Elias, Murphy & Council on Children with Disabilities, 2012). It is important to remember that not every child who requires complex medical care will end up at home with their family. Different families have different levels of health literacy, resources and capacity to support a child with complex medical needs. Some children may eventually live in out-of-home care, either in a foster family or in a long-term care unit.

Models of care are changing for families of children with complex health care needs. As parent access to technology improves, there is a great potential to provide better support via video over the internet, especially to families living in rural and regional areas. One example is the Chronic Pain Team at Sydney Children’s Hospital, Westmead, which provides support to families of children with chronic pain.

When children with complex needs become acutely unwell and need admission to hospital, it is critical to remember that the parents or the child’s primary caregiver(s) are often the experts in the care of their child.
They know their child best, and often detect subtle changes in the child’s behaviour or response before expert clinicians would. Parents may have had many years of experience in continuously caring for a child with a particular condition. If their child is dependent on technology, they often have a very good understanding of that technology, and have developed practical ‘know-how’ about the finer nuances of their child’s equipment. In these situations, health-care professionals can be somewhat intimidated by parents’ expertise! The best thing we can do is acknowledge and draw on that expertise to provide the best possible care for the child in partnership with the parents or caregiver(s).

Caring for a child with complex medical needs increases the burden of care for parents and family members. It can be difficult to assess the extent of the burden of care for a family. Each family has different capacity for function, and each child has different characteristics as an individual that can make caring for that child at home easier or more difficult (Pangilinan & Hornyak, 2013; Toly, Musil & Carl, 2012a). Depending on the nature of the child’s needs, there may be considerable time requirements for care and the need to learn a range of new skills and master new areas of knowledge (Kuo et al., 2011). To some extent, it is likely to be easier for families to adapt to managing a child’s illness at home when there are less demanding levels of care, skill or technology required, or the condition is non-life-threatening. When planning care, the cultural and social practices of the family should be considered, as these may impact on parent beliefs and values about the management of their child’s health.

Depending on the level of care required, parents may need to reconsider their commitments outside the home, and this can result in increased social isolation, potential decrease in income and increased costs for the care of their child (Cockett, 2012; Kuo et al., 2011). Mothers are
often the primary caregivers of children with complex needs, so may be at a higher risk of depression due to the burden of care (Toly, Musil & Carl, 2012b). The nature of the child’s condition may also mean that the child requires frequent hospitalisation, outpatient appointments and/or invasive procedures that may be intrusive on family life, cause pain and suffering for the child and increase the stress on parents and families (Kuo et al., 2011). Wherever possible, it is best to provide services to support children to remain at home with their families and within their communities, to enhance their opportunity to participate in normal, day-to-day life – for example, school, leisure activities and family life (WHO, 2012). While it may be ideal to discharge a child with complex needs to their own home as soon as possible, social, financial and environmental issues can delay discharge and prolong hospitalisation. For families such as Caleb’s, which live in rural or regional areas, access to specialist paediatric services can be a challenge. Outreach nursing services such as the CNC working with Caleb’s family act as an important link in the collaboration for Caleb’s care between specialist and local health-care services.

Caring for a child with complex needs can be demanding on parents, and some families may choose to take a break from the demands of caring for a child with complex needs. Respite care may be provided for brief periods of time at home, or overnight – either within the home or in another venue – by extended family, trained carers in the home or specific respite care organisations. Some parents may view an admission to hospital as a form of respite. Parents of children with complex needs can find it difficult to access community-based respite care that meets the needs and expectations of the child and the family (Dybwik et al., 2011; Ling, 2012).

Many children with complex health needs will have life-limiting conditions. For example, children like Caleb, with Duchenne’s muscular
dystrophy, may die in adolescence or early adulthood. Families such as Caleb’s will know this soon after a diagnosis is made, and will experience feelings of sadness and grief before Caleb passes away. Anticipatory grief can help parents, siblings and other loved family and friends to prepare and adjust for the time when their child is gone. For further discussion about palliative care, end-of-life care and grieving, see Chapter 12.

**Reflection points 11.1**

The proportion of children who survive childhood and adolescence with complex health-care problems is increasing due to advances in medical treatments and technologies. What are the implications of this trend for:

- families
- paediatric health-care professionals
- community health-care services for children
- school and education services?

**Nursing assessment and interventions**

A broad scope of conditions is associated with complex medical needs, and therefore the discussion of the range of likely nursing interventions is considerable and beyond the scope of this chapter. Instead, the more common nursing assessment and care issues are discussed, including respiration, mobility, nutrition and communication.
Respiration

Some children will require respiratory support as part of their condition, or as their condition progresses. This can take several forms, depending on the nature of the respiratory impairment, including the need for a tracheostomy, ventilation and/or oxygen therapy.

Children with chronic lung disease as a result of prematurity or disease may require long-term oxygen therapy. Sometimes children with neuromuscular conditions – even non-progressive conditions such as cerebral palsy – can develop chronic lung disease as a result of aspiration or reflux, and may require oxygen therapy (Kontorinis, Thevasagayam & Bateman, 2013). Children who are on long-term oxygen as a result of prematurity may eventually ‘outgrow’ their need for it. Children in this situation often require weaning from oxygen therapy under supervision in hospital.

Some children may require the creation of a tracheostomy and insertion of a tracheostomy tube to maintain a patent airway. Indications for a tracheostomy may include airway obstruction, difficulty maintaining a patent airway or the need for long-term ventilation (Bassham et al., 2012).

One of the issues with the creation of a tracheostomy is that the insertion of an airway into the trachea bypasses the upper airway. In normal respiration, the upper airway humidifies and filtrates the air before it reaches the lower airway, reducing the risk of infection. As a result, children with a tracheostomy tube would usually have a ‘Swedish nose’, or heat moisture exchanger, in place to help humidify and filter air.

Caleb will eventually require ventilation support as his respiratory muscles weaken. Initially, Caleb may only require non-invasive ventilation such as continuous positive airway pressure (CPAP) at night, to reduce the
likelihood of nocturnal hypoventilation (Wang et al., 2010). As his condition deteriorates, he may require insertion of a tracheostomy tube and continuous long-term ventilation. An increasing number of children requiring long-term ventilation are cared for in the community (Australasian Paediatric Respiratory Group, 2008). In order to care for children who require ventilation at home, families often require assistance from community-based carers, trained in the care of people who are medically stable but dependent on ventilation for survival.

Children like Caleb and Ahmed, with impaired respiratory function, are at higher risk of respiratory infections, and are more likely to require hospitalisation when unwell. It is essential that parents and health-care professionals know the child’s baseline parameters when they are well, are attuned to the signs of increasing respiratory effort and infection, and are trained in cardiopulmonary resuscitation. Additionally, parents and families need a clear plan for managing illness at home, and should know when and where to seek help from acute health-care services, including the ambulance service. For further information on physical assessment and the deteriorating child, see Chapter 8.

**Mobility**

Children who have motor impairment may have difficulty with mobility. It is important to bear in mind that the extent of motor impairment associated with different conditions can vary. For example, although Ahmed requires a wheelchair, not all children with CP will. On the other hand, motor impairment will get worse over time in some children with progressive conditions, as it has done for Caleb with muscular dystrophy. Regardless of the condition or prognosis, the main aim for children with motor
impairment is to maintain function and independence where possible, for as long as possible.

The care required by a child with motor impairment includes several priorities and a range of nursing interventions. One of the most important priorities is the prevention or delay of contractures and maintaining posture, as these factors are key to maintaining current level of motor function (Eddy, 2013). Physical therapy is an important intervention in terms of maintaining function, and requires a multidisciplinary approach from a range of health-care practitioners, including physiotherapists, occupational therapists and orthopaedic specialists (Pangilinan & Hornyak, 2013). Nurses and parents may be required to assist children in passive range of motion exercises, the application of splints, positioning to promote best posture and prevention or delay of scoliosis, which can result in difficulties with respiration as well as problems with mobility (Eddy, 2013). Depending on the extent of the impairment, children may require assistance with transferring or use of walkers, wheelchairs or standing boards. Any child with impaired mobility is at risk of skin breakdown and has a higher risk of falls. Nursing staff need to assess the level of risk for both skin breakdown and falls, and institute appropriate nursing interventions (Crisp et al., 2013).

Children with impaired mobility may require nursing assistance or have specialist intervention to meet their hygiene and elimination needs. Some children may not have bladder or bowel control, and may use nappies or incontinence pads, or need assistance to use a toilet or commode. Others may require intermittent urinary catheterisation or have an indwelling urinary or suprapubic catheter.

Whether nurses, other health-care professionals or parents are assisting children with mobility problems, it is important to adhere to the principles of manual handling. Carers can often become quite fatigued by
the physical demands of lifting and transferring children, and time should be made for rest.

**Nutrition and hydration**

Some children are unable to meet their hydration and nutritional needs due to difficulties with oral feeding, and may require enteral feeding via a nasogastric or nasojejunual tube, or gastrostomy. Nasogastric tubes are usually used as a short-term form of enteral feeding, as may be the case with Tobias, the baby boy with Down syndrome in *Case Study 11.3*. Children who require long-term or permanent enteral feeding are more likely to have a gastrostomy created and a gastrostomy tube or button inserted.

A gastrostomy is created via a surgical procedure under general anaesthetic. A puncture site (stoma) is inserted through the abdomen and into the stomach. Either a tube or button device is inserted into the stoma and may be secured with a suture. The tube or button device maintains patency of the stoma and acts as a conduit for fluid and formula. Similar to a nasogastric tube, the position of the tube or device is confirmed by aspirating gastric fluid and testing with litmus paper. There are several risks with the formation of a gastrostomy. The tube can migrate through the stomach and into the bowel, causing obstruction. Gastric secretions can ooze around the site, causing skin irritation.

Depending on the reason for enteral feeding, children may require bolus feeding during the day and continuous overnight feeds. In order to meet their metabolic needs for growth, children may have high-calorie feeds. Some children may require different types of formula, depending on their conditions.
Some children with complex medical conditions of the gastrointestinal tract may not be able to digest or absorb food and fluids. For these children, nutrition may need to be provided intravenously (parenteral nutrition), usually via a central venous access device (CVAD). Their need for parenteral nutrition may be temporary or permanent.

Ideally, it is better for children to maintain hydration and nutrition by feeding orally. Eating is a pleasurable experience, and an important milestone in language development. Some children may be able to take oral food and fluids, but may require assistance with drinking and feeding. Other children may have difficulty with swallowing, and may require pureed or mashed foods. In each of these instances, children should be supervised during meals to monitor for any signs of choking or aspiration.

When children are dependent on others for their nutrition, it is essential that their level of nutrition and hydration is monitored – both by regular measurements of height and weight to monitor growth, and by observing for signs of inadequate nutrition and hydration such as constipation and decreased urine output.

**Communication**

Some children with complex medical needs may have problems with speech, language or intellectual capacity. Any of these problems can reduce or interfere with their communication and understanding. Children with impairment in speech may use a variety of devices in order to communicate with others, from simple pictures to sophisticated computer-assisted devices.

Developing skills in communication with children who are well and developing normally can be challenging for health-care professionals, and it can be more complex when the child has difficulty communicating. The
principles of interpersonal communication are equally important for children with difficulty in communication. Our body language, the way we position ourselves to communicate, the tone of voice we use, the simplicity of the language we use – all of these are valuable ways in which we can enhance communication with children.

Again, parents are often a very good source of advice, as they understand the special ways in which their individual child communicates their needs to the world. This can be particularly important when caring for children with communication impairment when they are unwell. Parents are often able to interpret their child’s unique ways of communicating pain, fear or distress (Burkitt, Breau & Zabalia, 2011; Solodiuk et al., 2010). In addition to parent report, there are some specific pain-assessment tools that can be used when caring for children with severe disability, including the Non-Communicating Children’s Pain Checklist, the FLAAC tool and the Paediatric Pain Profile (McKay & Clarke, 2012).

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<td>Families vary in their cultural and social beliefs and values. For some families, their beliefs about people with complex medical needs will be influenced by their cultural background. Part of preparing to care for children with complex needs and disability means examining our own cultural beliefs, values and attitudes about children with disability, and being open and flexible towards people from different cultural backgrounds and their views.</td>
</tr>
<tr>
<td>- Do you have specific beliefs about the care of children or adults with complex medical needs?</td>
</tr>
</tbody>
</table>
Summary

- Children with complex needs and their families are frequent consumers of acute paediatric health-care services due to higher risk of acute illness.
- Although different types of conditions that result in complex medical needs are ‘rare’, they are ‘common’ in the children requiring acute paediatric health care.
- The impact of complex medical needs on day-to-day life for children and families is individual and complex.
- Parents and primary caregivers of children with complex health-care needs have special expertise regarding their child, and specialist knowledge of the condition as it relates to their child.
- There is considerable variation between individual children and their individual nursing needs; however, nursing interventions for issues associated with impairment of respiration, mobility, nutrition and communication may be required.

Learning activity

The nature of health-care funding in Australia means that there is often some variation between local areas in the provision of resources to support the care of children with complex needs, depending on whether the
funding is provided at a state or territory, or at the Commonwealth level. It is useful for nurses and other health-care professionals who care for children with complex needs to have an understanding of the availability of resources and funding for families, and to know where to locate this information.

In this activity, use the internet to undertake a search of resources in your area for children with a specific complex medical need and their families. Use Table 11.1 as a template to begin with, but you may have additional information that you may want to add to your search. An example (based on the Carer Allowance) is provided to help you get started.

Table 11.1 Resources for children with complex medical needs

<table>
<thead>
<tr>
<th>Resource</th>
<th>Funding source</th>
<th>Details</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Allowance</td>
<td>Commonwealth government</td>
<td>The carer must be caring for one or more dependant children under 16 years with a recognised disability or medical condition lasting 12 months or</td>
<td><a href="http://www.humanservices.gov.au">www.humanservices.gov.au</a></td>
</tr>
</tbody>
</table>
longer and receiving care in home or hospital

Pharmaceutical cost assistance

Equipment supplies

Respite care

School information

Disease/condition support network

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)
Costs associated with hospital admissions

Further reading

The most common issues that parents of children with complex health care problems report are:

- their need for social support, particularly from parents of other children with their child’s condition
- information needs.

In Australia, we have a wide range of consumer groups for families of children with rare conditions. In this activity, you are encouraged to locate the parent support organisation for one of the conditions outlined in this chapter. Review the resources, information and any social networking activities it offers. Having a good knowledge of the support networks available to parents is a useful tool for nurses. The Association for the Wellbeing of Children in Healthcare (AWCH) is a good place to start. This non-profit organisation of parents, health-care professionals and other interested community members advocates for children and families who access health care in Australia. It is a supporter of the World Rare Diseases Day, and has links to various groups. See the AWCH website for details: www.awch.org.au/index.php.

References


Solodiuk, JC et al. 2010, Validation of the Individualized Numeric Rating


**Children with complex medical needs** – Defined as those children with substantial family-identified needs, characteristic complex and/or
chronic conditions, functional limitations and high health-care use

| **Cerebral palsy (CP)** – An umbrella term for non-progressive but often changing motor impairment that occurs before or soon after birth |
| **Muscular dystrophies** – A group of neuromuscular genetic disorders that result in the progressive deterioration of muscle strength and function |
| **Phenylketonuria (PKU)** – A metabolic disorder that is present at birth and caused by an autosomal recessive gene. Essentially, the condition results in a failure to metabolise phenylalanine, an amino acid found in proteins and some artificial sweeteners. If PKU is undetected and not treated, it can cause a range of serious health effects, including intellectual disability and seizures. It is important that it is detected early in life to prevent these complications. |
| **Premature birth** – The live birth of an infant before 37 weeks’ gestation (WHO 2015) |
| **Down syndrome** – A series of chromosomal disorders that occurs in chromosome 21. Usually we are born with two copies of chromosome 21, but most children with Down syndrome have three copies (standard trisomy 21). There are two other less common forms of Down syndrome: mosaicism, where some cells have trisomy 21 but others do not; and translocation, where part of chromosome 21 has attached to another chromosome. Children with mosaicism exhibit some but not all of the characteristics of trisomy 21. Children with trisomy 21 or translocation will present with all the characteristics of Down syndrome. |
| **Respite care** – Temporary care provided to children with complex needs by another, to provide parent(s) or primary caregiver(s) with the opportunity for a break from the demands of care |
| **Anticipatory grief** – The experience of the grief response, when the
child or person is expected to die at some point in the future as a result of illness or disability
End-of-life and palliative care in Australian paediatric care settings

Elizabeth Forster

Learning objectives

In this chapter you will:

- Develop an understanding of the physical and psychological problems experienced by children in end-of-life care
- Develop an understanding of some of the strategies used to address or manage these problems in paediatric end-of-life care
- Consider the importance of communication with the child/young person, parents, siblings and grandparents in paediatric end-of-life care
- Explore ways to support parents, siblings and grandparents in paediatric end-of-life care
Introduction

Although children in Australia enjoy a long life expectancy and high level of wellbeing, paediatric death remains a sad reality for some families, and end-of-life care for children presents an important and challenging area of paediatric nursing practice.

The rate of child mortality in Australia more than halved from 30 to 13 deaths between 1986 and 2006, due to a reduction in the number of paediatric deaths from transport-related accidents; however, the mortality rate stabilised between 2006 and 2010 (AIHW, 2012). Among children aged 1–14 years between 2008 and 2010, the leading causes of death included injury (34 per cent), cancer (17 per cent) and nervous system diseases (11 per cent) (AIHW, 2012).

As a beginning paediatric nurse, it is important that you understand that the terms paediatric palliative care and paediatric end-of-life care are conceptualised differently, despite some overlap. Paediatric palliative care begins when a disease is first diagnosed, and continues throughout the illness trajectory. It therefore includes, but is not limited to, end-of-life care (Crozier & Hancock, 2012). The majority of paediatric palliative care is delivered by hospital-based or community teams in the last six months of a child’s life (Crozier & Hancock, 2012). Paediatric end-of-life care is the care provided to the child and family towards the end of a child’s life, and includes care of the child’s body and support for the family following the child’s death. Although there are distinctions between the two terms, in this chapter they will be used interchangeably.

The World Health Organization (WHO) definition of palliative care for children was developed in 1998 in recognition that paediatric palliative care, although related to adult palliative care, is a distinct and specialised area. The WHO (1998) definition includes the following principles:
Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.

It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Health providers must evaluate and alleviate a child’s physical, psychological and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be implemented successfully even if resources are limited.

It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

Central to paediatric end-of-life care are the frequent and comprehensive assessment and management of physical and psychological symptoms, facilitating effective and developmentally appropriate communication with the child and family, individualised holistic care with a focus on quality rather than quantity of life, and the involvement of a multidisciplinary team of health professionals (Stayer, 2012).

Paediatric end-of-life care occurs in a variety of contexts, including the acute paediatric setting and the community, in hospice care and in the child’s home. The trajectory or path of a child and family’s journey from diagnosis to end-of-life care will vary, and for some families this journey may be as short as a few days or weeks, or as long as many years in the case of chronic conditions.

This chapter will provide you with a beginning understanding of some of the common symptoms and concerns for children in end-of-life
care and their management, including pain, the management of side-effects of opioids, fatigue, dyspnoea, gastrointestinal disturbances and anxiety. It will also discuss communication with dying children and adolescents, and the importance of family communication and support.

**Pain**

Pain assessment in children is a complex area requiring keen observation skills and effective, age-appropriate communication. Paediatric pain assessment is discussed in more detail in Chapter 8, and it is recommended that you revise this chapter in relation to the assessment of paediatric pain. In this chapter, paediatric pain management in end-of-life care will be the main focus of discussion. As a foundation for understanding pain management in end-of-life care, it is helpful to review the WHO analgesic ladder.

**The WHO analgesic ladder**

WHO first introduced the analgesic ladder in the 1980s as a guide for the management of cancer pain. Previous versions of the analgesic ladder have now been updated and a two-step ladder is now recommended for children (Downing et al., 2015; WHO, 2012). The two-step approach excludes ‘weak opioids’ such as codeine and tramadol, which did not meet the guidelines for safe use in children (Downing et al., 2015). It retains recognition of the need for a step-up and step-down approach to pain relief. In conjunction with the two-step analgesic ladder for pain management for children, the WHO guidelines recommend using regular dosing schedules by the clock rather than as-needed prescriptions, together with consideration of the individual needs of each child experiencing pain.
and administering pain relief by the most appropriate route – preferably oral or other non-invasive routes (WHO, 2012).

Non steroidal anti-inflammatory drugs (NSAIDs) such as paracetamol and ibuprofen are recommended for mild pain. NSAIDs are frequently used to manage mild pain for children in palliative care due to their effectiveness in inflammatory causes of pain; they are also helpful for pain due caused by bony metastases (Dowden, 2014). The WHO ladder recommends the use of opioids such as morphine for severe pain. Although such opioids remain effective for the management of severe pain, unfortunately they have a variety of side-effects that can increase the suffering of children if not managed promptly and appropriately.

![Diagram of the two-step WHO analgesic ladder recommended for children](Image)

**Figure 12.1** The two-step WHO analgesic ladder recommended for children

Source: Adapted from Downing et al. (2015).

**Side-effects of opioids**

Although opioids such as morphine can provide good pain relief for moderate to severe pain, there are many side-effects related to their use that may need to be addressed. More common side-effects include
constipation, pruritus, and nausea and vomiting; less common side-effects are urinary retention, respiratory depression and myoclonus (Shaw, 2012). Table 12.1 lists some side-effects of opioid analgesia and strategies that may be used to manage these.

**Table 12.1 Side-effects of opioids and strategies to address these**

<table>
<thead>
<tr>
<th>Opioid Side-Effect and Cause</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Constipation</strong></td>
<td>Preventative management with stool-softeners at initiation of opioid treatment.</td>
</tr>
<tr>
<td>Decreased intestinal motility due to opioid</td>
<td></td>
</tr>
</tbody>
</table>

| **Pruritus** | Pruritus will usually resolve within a few days, but antihistamines may need to be prescribed by the medical officer. |
| Benign side-effect due to histamine-releasing properties of opioids | |

| **Nausea and vomiting** | Antiemetic therapies such as Ondansetron or Metoclopramide may need to be prescribed by the medical officer. |
| An initial side-effect of opioids, but may also be linked to constipation | |

| **Urinary retention** | Try techniques such as running water and Crede’s manoeuvre. |
| An uncommon side-effect of opioids | |
**Respiratory depression**

Accurate assessment is required to distinguish between a reduced respiratory demand and slowing of respirations that may normally accompany a reduction in pain intensity and true respiratory depression.

Very rare when appropriate opioid doses and titration are used.

Respiratory depression is usually preceded by a decreased level of consciousness and somnolence.

Excessive slowing of respiration rate may be managed by rousing the child, slowing the rate of the opioid infusion or administering oxygen.

Reversal agents such as naloxone should be used cautiously, as they rapidly reverse pain relief, which may lead to severe pain and may result in life threatening opioid withdrawal.

**Myoclonus**

Brief involuntary twitching that may occur when high doses of

Rotating to a different opioid may be a consideration, or the medical officer may need to prescribe benzodiazepines or muscle
opioids are used, or if they are administered over a long period and are due to an accumulation of metabolites, which have neuro-excitatory effects-relaxants.

Source: Adapted from Klick & Hauer (2010); Shaw (2012).

As a beginning clinician working in palliative care, you will need to familiarise yourself with the usual doses of medications commonly prescribed in paediatric palliative care. Table 12.2 provides an overview of some of the common opioids prescribed for children in palliative care and their usual starting dosages.

Table 12.2 Starting doses for opioid analgesia in micrograms per kilogram of child’s weight

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Morphine</strong></td>
<td>50–100 mcg/kg/dose</td>
<td>Every 2–4 hours as prescribed</td>
</tr>
<tr>
<td>Oral</td>
<td>200–400 mcg/kg/dose</td>
<td>Every 4 hours as prescribed</td>
</tr>
<tr>
<td><strong>Oxycodone</strong></td>
<td>100–200 mcg/kg</td>
<td>Every 4–6 hours as prescribed</td>
</tr>
<tr>
<td>Oral</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fentanyl</strong></td>
<td>1–2 mcg/kg/dose</td>
<td>Every 1–2 hours as prescribed</td>
</tr>
<tr>
<td>Intravenous</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Non-pharmacological pain relief

In addition to the pharmacological management of pain in paediatric end-of-life care, non-pharmacological strategies have an important complementary role to play. Non-pharmacological pain relief strategies may range from cognitive/behavioural techniques and distraction to strategies involving physical touch, including skin-to-skin contact for infants or massage (Levine et al., 2013).

Cognitive and behavioural techniques encompass a variety of strategies, including guided imagery, hypnosis, relaxation, distraction, storytelling, music and art therapy, and play therapy (Hyde, Price & Nicholl, 2012; Monterosso & DeGraves, 2012). These approaches acknowledge that pain involves both physical and psychological elements, and although more research evidence is needed regarding their use in children, many of these cognitive and behavioural strategies may be helpful in targeting perceptions of pain and therefore contribute to overall pain relief.

Massage is commonly used by parents for a variety of health and discomfort-related problems (for example, infant colic, stress reduction, relaxation, sleep problems and musculoskeletal pain), and is also often used in the health-care setting for relieving discomfort associated with procedures and as a complementary therapy in paediatric cancer (Hughes et al., 2008). A systematic review of the use of massage among patients with cancer, including those in palliative care, has been conducted and some evidence has been found for its benefit in cancer palliation and supportive care (Ernst, 2009). However, as with many non-
Pharmacological approaches, more research is needed, particularly in paediatric palliative care, to establish its effectiveness (Ernst, 2009; Schutze et al., 2016).

**Reflection points 12.1**

- Paediatric end-of-life care encompasses the physical, psychosocial and spiritual care of the child, and support for the family leading up to and following the child’s death. It may be provided in a hospital or hospice, or at home. How might the setting in which end-of-life care is provided influence your role as a paediatric nurse?

- The two-step WHO analgesic ladder was developed as a guide for the management of pain in children and has a step-up and step-down approach. Why might a step-down approach to pain management be important for paediatric end-of-life care, especially when this care may be delivered over a long period of time, as in the case of life-limiting conditions?

- Opioids such as morphine remain a commonly used analgesic in paediatric end-of-life care; however, they have many side-effects. Why is the ability to assess and manage these side-effects so important for paediatric nurses working in end-of-life care?

- Non-pharmacological pain-relief strategies may also be used to complement pharmacological pain relief in paediatric end-of-life care. Consider some of the non-pharmacological approaches you have seen used in clinical practice. How might these be useful in paediatric end-of-life care? Conduct a database search to find
Fatigue

Fatigue is a difficult concept to define, but most agree that it involves both physical and psychological facets. Fatigue remains one of the most common problems experienced by children at end of life (Tomlinson et al., 2011; Ullrich et al., 2010; Wolfe, Grier & Klar, 2000) and has been found to increase as children near death (Tomlinson et al., 2011). Fatigue can comprise both physical and psychological symptoms, and the descriptions of children and adolescents range from not being able to engage in the activities they enjoy, not being able to participate independently in daily activities, and needing to sleep and rest more often to psychological impacts such as feeling sad, guilty, emotional, annoyed and powerless (Tomlinson et al., 2016). Some examples of children’s descriptions of fatigue can be found in Table 12.3.

Table 12.3 Child and adolescent descriptions of fatigue

<table>
<thead>
<tr>
<th>CHILDREN AND ADOLESCENTS’ DESCRIPTIONS OF FATIGUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Finding it hard to walk, move or run, or participate in sport, physical activities or school</td>
</tr>
<tr>
<td>• Feeling like laying around, needing to lie or sit down, or feeling exhausted, drained, weak and tired with no energy and wanting to do nothing</td>
</tr>
</tbody>
</table>
Fatigue is a multidimensional problem experienced by dying children, and has been found to be associated with other symptoms such as nausea and vomiting, diarrhoea, nutritional impairment and anaemia, sleep disturbances (especially during hospitalisation) and psychological experiences such as fear, anxiety and sadness (Ullrich et al., 2010). It may also be linked to the side-effects of pain and dyspnoea treatments such as opioids and sedative medications (Ullrich et al., 2010).

Paediatric nurses should use valid and reliable tools/scales to assess for fatigue in children. One assessment scale that has been developed and used to measure fatigue among paediatric cancer patients is the Fatigue Scale – Child for 7–12-year-olds, which was developed by Hockenberry and colleagues (2003). This scale contains 14 items that are completed by the child using a Likert scale format, with total fatigue scores from 0 indicating no fatigue symptoms to 70 indicating high fatigue. More

- Feeling sad, upset, irritable, annoyed or mad, or feeling upset when you are emotionally tired
- Feeling not able to play or talk with friends when they visit or call and not wanting to be disturbed by others
- Physical signs such as difficulty keeping eyes open, having a dull face and tired eyes, and feeling dizzy, nauseous or hot and cold flushes
- Feeling sorry for yourself and feeling mentally tired for having to go through so much
- Feeling sleepy or drowsy and falling asleep easily and having disturbed sleep

Source: Adapted from Tomlinson et al. (2016) Hockenberry-Eaton et al. (1998).
recently, this tool has been reduced to a 10-item scale (Hinds et al., 2010). Children completing the scale rate statements such as ‘I have been tired’, ‘My body has felt different’ and ‘I have been tired in the morning’ (Hockenberry et al., 2003: 322).

Fatigue has been described as difficult to treat and manage, although a variety of strategies have been employed in an effort to manage this distressing problem. A small number of studies in paediatric patients undergoing treatment for cancer have investigated exercise for fatigue management; however, the utility of this intervention in end-of-life care is uncertain, due to the child’s deteriorating physical condition (Chang et al., 2013). Massage, together with strategies to promote nutrition and energy conservation that have also been used in paediatric cancer studies (Chang et al., 2013), and may be more appropriate for children in end-of-life care. Fatigue among children at end of life may be relieved through the management of sedative effects of opioid medications, reducing anorexia, nausea and vomiting, and improving nutrition, and by addressing sleep disturbances and distressing psychological issues such as sorrow and anxiety (Ullrich et al., 2010). The multifaceted nature of fatigue, and its diverse influencing factors, make it challenging to manage, and further research is needed in paediatric end-of-life care to determine the most effective strategies to combat this problem.

Dyspnoea

Abnormal or difficult breathing is another symptom experienced by children in end-of-life care, and is a cause of distress to both the child and the family (Pritchard et al., 2008).

In children, dyspnoea usually occurs due to a combination of:
• increased work of breathing linked to increased airway resistance, decreased lung compliance or decreased muscle strength or abnormality

• increased ventilation requirements due to metabolic acidosis, hypoxaemia, anaemia or other physiological states (Robinson, 2012).

The management of dyspnoea in paediatric palliative care requires a weighing up or balancing of the burden of treatments, which may be quite aggressive and upsetting for the child, versus the more conservative management of symptoms. This needs to be negotiated constantly between health professionals and the child (if appropriate) and parents (Robinson, 2012). In palliative care, the pathophysiological cause of the dyspnoea may not be pursued, and instead the focus will be on the management of the dyspnoea to ensure the child’s comfort.

It is important to acknowledge the psychological relationship with dyspnoea and physiological processes, as this highlights the importance of management strategies that will be targeted towards the child’s perceptions, thoughts and feelings about their dyspnoea as well as the underlying physiological processes. A useful way to remember this relationship is to consider how you feel after a long, strenuous aerobic exercise session, where you are struggling to regain your breath and feeling a sense of chest tightness or dyspnoea. Because you are not alarmed by this mentally, and understand that it is a normal and even desirable response under the circumstances, you feel quite calm as you know it will resolve in a few minutes. However, if you are very ill and you start to experience difficulty breathing, then your cognitive state would likely be quite different: you would likely begin to worry, become fearful
and experience a sense of panic. We must consider the cognitive and affective relationship with dyspnoea:

In addressing the suffering associated with dyspnoea we must consider the fact that the mind is not only an agent through which suffering is experienced or perceived, but it also is an active participant in the physiology of dyspnoea.

(Hallenbeck, 2012: 849)

Parental perceptions are a vital component of the management of dyspnoea in paediatric palliative care, as a child will usually look to their parents to gauge how to interpret most situations. It is very important that parents receive support and education about the possibility that their child may experience breathing difficulties in palliative care, and the importance of remaining calm and reassuring in their child’s presence to avoid exacerbating the child’s negative perceptions of their dyspnoea, which will in turn worsen their breathing difficulties.

Both non-pharmacological and pharmacological strategies can be used to relieve dyspnoea in children. Non-pharmacological strategies include behavioural interventions such as behaviour modification and techniques to reduce anxiety and controlled breathing techniques. The use of fans to increase circulating air and blow air over a child’s face may also be helpful, as some studies using nasal prong flow of air across the nasal passages have achieved relief from dyspnoea in some patients, although the exact mechanism of action is unknown (Abernethy et al., 2010; Craig, Henderson & Bluebond-Langner, 2015; Robinson, 2012; Ullrich & Mayer, 2007). The main pharmacological strategy for the management of dyspnoea in both adult and paediatric patients is the use of opioids such as morphine. Other strategies may include the use of assisted non-invasive
ventilation such as BiPaP or CPAP, but these may not be tolerated well by paediatric patients (Craig, Henderson & Bluebond-Langner, 2015). They may, however, be used at night and during sleep periods to counteract respiratory muscle fatigue, which may enable a child to have more energy to participate in daytime activities (Robinson, 2012). It is important to consider that parents may not want to have their view of their dying child’s face obstructed by the masks used in non-invasive ventilation (Ullrich & Mayer, 2007), and this is another example of balancing the need for treatments and their associated burdens for the child and family.

In addition to dyspnoea, paediatric palliative care patients may also experience discomfort relating to frequent coughing, increased secretions and possibly haemoptysis (Craig, Henderson & Bluebond-Langner, 2015). Although more research is needed to determine the best management in children, there are some strategies that can be effective for paediatric patients. Coughing may be linked to impaired swallowing and aspiration or reflux, and in these situations alternative feeding methods may be needed to reduce the risk of aspiration and pharmacological therapies may assist with reflux (Craig, Henderson & Bluebond-Langner, 2015). Physiotherapy and suctioning may also provide some relief from increased secretions. Haemoptysis may occur in some children at end of life, and this is a distressing occurrence for the child and their family, as well as for the health-care team (Forster, 2012). Efforts are usually made to minimise the visual impact of bleeding through the use of dark-coloured towels, and opioids and anxiolytics such as morphine and midazolam can be used to reduce the child’s breathlessness and distress in the event of this occurring (Craig, Henderson & Bluebond-Langner, 2015).

**Gastrointestinal disturbances**
There are a variety of gastrointestinal (GI) disturbances that may create unnecessary discomfort for children in palliative care, including constipation, nausea and vomiting. These GI disturbances, as mentioned earlier in this chapter, may be linked to opioid administration. Table 12.1 listed some strategies to combat these side-effects of opioid analgesia. In relation to constipation, it is important for paediatric nurses to assess the child’s risk as well as stool characteristics. A variety of factors, including the use of opioid medications, limited mobility and a deterioration in both food and fluid intake, can place the child in palliative care at increased risk of constipation. The Bristol Stool Form Scale is a useful visual scale for determining the characteristics of the child’s stool, and is easy to use for the child and parents because of its visual depictions (Stewart & McNeilly, 2011).

Nausea and vomiting may also be linked to biochemical and vestibular factors, and disturbances in gastrointestinal motility and function, including decreased motility, malignancies, ascites, adhesions and obstructions or neurological disturbances resulting in raised intracranial pressure, which may impact on the chemoreceptor trigger zone (CTZ) of the brain and the vomiting centre in the medulla oblongata (Yates, 2012).

Weight loss and cachexia may also occur in paediatric palliative care. Cachexia has its origins in the Greek words kakos (bad) and hexas (condition), and refers to the loss of appetite, weight and muscle mass that results from an underlying pathological condition, including those seen in palliative care. The physical appearance of their dying child may be distressing for parents (Forster, 2012) and body image and appearance changes that occur as a consequence of treatment may also be a significant concern for children and adolescents with life-limiting illnesses at times.
throughout their illness trajectory (Choquette, Rennick & Lee, 2016; Lee et al., 2012).

Nutritional intake may decrease as a child nears end of life, and children will usually be offered small amounts or tastes of foods and fluids as desired, which can be comforting (Crozier & Hancock, 2012). However, sometimes changes such as coughing, gagging and difficulty swallowing may make it difficult and uncomfortable for dying children to eat and drink. Although artificial nutrition and hydration (via nasogastric or parenteral routes) may be considered, these interventions have associated complications, and the palliative care team in partnership with parents will usually weigh up the risks versus the benefits of commencing artificial nutrition (Rapoport et al., 2013). At this stage ‘although artificial nutrition and hydration may support biological existence and increase weight, there is no evidence that it improves survival or quality of life in dying children or adults’ (Rapoport et al., 2013: 862). Parents, however, will often feel a strong desire to continue to provide nourishment to their dying child, and may be concerned about their child feeling hunger and thirst, and being uncomfortable if adequate nutrition and hydration are not provided (Pritchard et al., 2008; Rapoport et al., 2013). This is an extremely difficult and emotionally painful time for parents, and any decisions concerning whether to implement or forgo artificial nutrition and hydration need to be supported by the palliative care team. Parents need to be reassured that it is normal for appetite to diminish towards end of life, and that their child will likely not feel the desire to eat or drink.

**Case study 12.1**

Matthew is an 11-year-old boy with acute myeloid leukaemia who is receiving palliative care support after an unsuccessful stem cell
transplant. You are visiting Matthew and his family each day at home with the palliative care team. He is surrounded by his parents and younger sister, who is 6 years old. Today you notice that Matthew is struggling to breathe and is quite distressed. Matthew says that he has pain in his stomach and lower back and can’t breathe. He spends some time each day sitting out in the recliner chair in the lounge room, which seems to help with his lower back pain. He has not been eating much in the last few days – just a small amount of milk and cereal each day in the morning and a small taste of whatever the family is eating for dinner.

Anxiety

Children and parents have reported experiencing distressing emotional reactions during their experience of terminal illness. These include feeling scared or nervous, dealing with uncertainty, fear of death, thinking about being sick and questioning ‘Why me?’ (Hildenbrand et al., 2011). The reduction of anxiety for children during end-of-life care is important, as it not only creates distress for the child but also can have an ongoing impact on parental anxiety and mental health (Jalmsell et al., 2010). Children and their parents may utilise a variety of coping strategies, which either avoid or address these distressing emotional issues (Hildenbrand et al., 2011). Music therapy, for example, has been found to promote a sense of calm and relaxation among children in palliative care and their families (Lindenfelser, Hense & McFerran, 2012). Communication concerning issues of concern may also be important for reducing anxiety. In a study among adolescents with cancer, participating in a structured, family-centred, advanced care planning program significantly decreased anxiety
among adolescents, but unfortunately increased anxiety among family members (Lyon et al., 2014). The program enabled adolescents with cancer and their families to engage in reflection and discussion about their fears, values, spiritual beliefs and preferences in relation to future treatments and care, as well as palliative care (Lyon et al., 2014).

**Communication with children and adolescents**

Effective end-of-life care for young people increasingly emphasises the importance of engaging in conversations about dying and advanced care planning because adolescents possess growing cognitive and emotional maturity, which means they understand death and want to be involved in decisions concerning their treatment and end-of-life care (Lyon et al., 2014). Sometimes such conversations may be avoided by health professionals, leaving young people struggling to find ways to communicate their thoughts and feelings about the possibility of their own impending death (Forster, 2012).

There are a variety of reasons why such conversations may be avoided or delayed, including health professional discomfort or lack of confidence, uncertainty about the legal competence of a teenager to make decisions regarding their own care and fears about diminishing the adolescent and or family’s sense of hope (Wiener et al., 2013). Parents may also not want such conversations to be initiated as they too may be concerned about leaving the impression with their adolescent that further treatments are unlikely to be successful (Wiener et al., 2013). Whether an adolescent is ready to discuss such issues is currently being researched, and it is important for nurses to recognise that an adolescent’s readiness
involves a complex interplay of emotional and cognitive preparedness, acceptance and willingness (Bell et al., 2016).

There are a number of paediatric advanced care planning models that have been developed primarily in the United Kingdom and United States with particular target groups of adolescents, including Footprints (designed for patients with muscular dystrophy), the Family-Centred (FACE) Advanced Care Planning for young people with HIV, and FACE-TC, which adapted this model for teens with cancer (Lyon et al., 2014). In a study of 30 adolescents with cancer, participating in advanced care planning conversations significantly reduced the anxiety of the adolescent (Lyon et al., 2014). These models were delivered by health professionals who undertook specialised training, and the conversations with the adolescent and their family occurred over a number of sessions (Lyon et al., 2009).

There are also models that have been developed for adolescents and young adults such as the Voicing my Choices™ advanced care planning guide (Zadeh, Pao & Wiener, 2015). This guide addresses a variety of areas that may be significant for the adolescent at end of life, including:

- how they would like to be supported so that they don’t feel alone
- how they want to be comforted in terms of food, readings, music and pain medication
- who they want to make medical treatment decisions for them if they are unable to make these decisions independently
- preferences for life-support treatments
- what they want their friends and family to know about them
- spiritual thoughts and preferences
• how they want to be remembered

• an opportunity to express their own voice through legacy letters to their loved ones.

It is recommended that conversations about advanced care planning with adolescents begin early in their illness trajectory and not during a period of deterioration or crisis, and that they then should occur at regular points throughout their treatment and care (Zadeh, Pao & Wiener, 2015). Normally, experienced health professionals who have undertaken specific educational preparation will initiate and facilitate such conversations and you, as a beginning paediatric nurse, may have the opportunity to accompany an experienced colleague during such meetings. It is important to keep in mind that many health professionals experience discomfort with these conversations (Zadeh, Pao & Wiener, 2015; Lotz et al., 2015) and are often not sure about how to initiate such conversations. One approach to initiating such conversations has been developed, and may be a helpful way to broach such discussions (Zadeh, Pao & Wiener, 2015: 594):

Although we are hoping that this next treatment will be helpful, many people your age have told us that they found it helpful to have a say about what they would want or not want if treatment doesn’t go as expected. In fact, people your age helped create a guide so that they could put down on paper the things that are important to them.

This approach, from the Voicing my Choices™ advanced care planning guide, recommends using words like ‘in our experience, we have found young people your age often find it important to talk about’ or similar words as an entrée into discussion of each element of the advanced care plan (Zadeh, Pao & Wiener, 2015).
Younger children may also want to discuss their worries and fears. Play and art therapy are two strategies that may be used to enable younger children to communicate their worries. Play and art therapy can assist paediatric nurses to understand the problems a child is facing, to help the child to verbalise conscious feelings and thoughts, and to act out subconscious feelings and thoughts (Van Breemen, 2009; Walker, 1989). Nurses can also assist parents to engage in play with their child, and by doing so parents may also gain insights into their child’s fears and hopes (Van Breemen, 2009).

For the student and beginning nurse, it is important to be aware of the possibility that paediatric patients and their families will want to discuss their thoughts and feelings about death and end-of-life care, and to be alert to possible cues that indicate this need. Your confidence in responding to such cues and engaging in end-of-life conversations will develop through further training and experience. In the meantime, being able to listen to young people and their families, and involving other health professionals when necessary, is important to ensure that any need to discuss these issues is facilitated. By attending family conferences, you will also have the opportunity to observe more experienced health professionals and their communication with children and families in palliative care (Keir & Wilkinson, 2013). This will provide a good opportunity for you to observe body language and the ways in which experienced health professionals express empathy and engage parents – and, if appropriate, the child – in difficult conversations and respond to intense emotions.

**Communication and the family in paediatric end-of-life care**
Parents of dying children place great emphasis on the communication with health professionals during their child’s illness and around the time of their child’s death (Meyer et al., 2006). There may be a tendency among health professionals to avoid communication with parents and family members at this time, and to focus on the technical aspects of care (Forster, 2012). However, sensitive and supportive communication is central to the quality of end-of-life care in paediatrics, and can help parents and family members through this overwhelming and devastating time.

Parents caring for their dying child at home may feel quite uncertain about the physical aspects of their child’s care, and may struggle to navigate the emotional aspects of facing their child’s impending death. In one Australian study, parents described wanting to talk with health professionals about their feelings, but finding that nurses and doctors did not introduce such topics of conversation (Forster, 2012). Therefore, nurses need to find the time to engage with parents about their thoughts and feelings in order to offer their supportive presence. Parents may feel unable to discuss such feelings with friends and in their social circle, and may feel isolated and alone. In addition, with strain upon both parents simultaneously, they may feel unable to fully support each other while going through their own feelings of grief (Moriarty, Carroll & Controneo, 1996).

It is important that the team of health professionals involved in end-of-life care provides consistent and frequent information to families. The team should also recognise that complex information (even when explained in simple terms) may require repetition, and that parents may need regular meetings in order to be able to make decisions about their child’s ongoing care (Crozier & Hancock, 2012).

**siblings**
Siblings of the dying child also require support and consideration, as they can be impacted in multiple ways during the course of their brother’s or sister’s illness and end-of-life care. Their understanding of the situation will be influenced by their age and stage of development, and this will also guide the strategies employed by nurses and the palliative care team in providing effective support.

Often, siblings have had their usual experiences of family life interrupted and changed due to the illness of their sibling. They may have had to experience being cared for by other family members and friends; they may have been required to take on additional responsibilities; and they have, of course, lost time and contact with parents who may have been focused on the care of a sick and dying sibling (Foster et al., 2010). Siblings are also struggling with their own emotional responses to their brother’s or sister’s illness and impending death, and may experience fear, anger, jealousy, shame and guilt, and feel isolated and forgotten (Foster et al., 2010). Siblings are also often acutely aware of their sibling’s condition and may not reveal this to their parents in order to protect them from the ensuing sadness; similarly, parents may not engage in these discussions with their well children for the same reasons (Malcolm et al., 2014).

In their study of 18 siblings aged 9–22 years in New Zealand, Gaab, Owens and MacLeod (2014) found that siblings wanted to be informed about the impending death of their sibling, and to be included in conversations about symptoms so that they could understand what was happening. These preferences were also balanced by the negative aspects of having this knowledge, as siblings then worried more – for example, that their sibling would go to sleep and not awaken, or that conversations about death and dying were then brought up too much and this made it difficult to live as normal a life as possible. Siblings also engaged in
helping behaviours and spent time with their sibling, trying to make them smile and stay positive (Gaab, Owens & MacLeod, 2014).

Nurses and the palliative care team can support siblings by:

- involving them in discussions about care and treatment throughout their sibling’s illness
- enabling siblings to be involved in caregiving if desired
- assigning a social worker or supporter to specifically work with siblings
- putting families in contact with relevant sibling support groups
- educating the family about the needs of siblings when a child is sick and dying
- encouraging siblings to continue to be involved in their own interests and pursuits
- helping the family to identify a ‘safe adult’ in the siblings’ world to whom they feel they can talk about their feelings and concerns
- providing referrals to psychologists and counsellors when necessary
- asking siblings about their feelings and experiences (Jenholt Nolbris & Nilsson, 2016; Jones, Contro & Koch, 2014).

**Grandparents**

Grandparents often play a central role in supporting parents and families when a child is ill and dying (Moules et al., 2012), and therefore also need to be supported at this time and following the child’s death. Grandparents have been described as experiencing threefold layers of grief when losing
a grandchild, as they are grieving the loss of their cherished grandchild, for their son or daughter who is losing/has lost a child and for themselves (Ponzetti & Johnson, 1991). Grandparents may not discuss their own emotions and inner turmoil because of a need to be strong for their adult child and other grandchildren, and they may prioritise the needs of these family members above their own (Moules et al., 2012; Youngblut et al., 2010; Youngblut et al., 2015). It is important for nurses to be aware of grandparents’ feelings, and to provide opportunities for them to talk about their feelings and concerns and to access support services (Youngblut et al., 2010; Youngblut et al., 2015). In addition, because grandparents are often not directly involved in parent and palliative care team meetings, they may have questions about their grandchild’s condition and management (Wakefield et al., 2016); paediatric nurses are well positioned to provide this informational support.

**Summary**

- Although child mortality in Australia has halved since 1986 and stabilised between 2006 and 2010, for some families the death of a child remains a sad reality. The leading causes of paediatric death include injury, cancer and nervous system diseases. These children and their families require specialised end-of-life care that recognises and supports the unique needs of the dying child and their family. Paediatric nurses play a central role in the coordination and provision of this care.

- Paediatric palliative or end-of-life care involves the physical, psychosocial and spiritual care of the child and their family. Its commencement and duration may vary, depending on the child’s...
illness and trajectory, and it may be provided in a variety of settings, including hospitals, community care, hospices and the child’s home.

- Children may experience a variety of problems at end of life, including pain, side-effects of opioid medications, fatigue, dyspnoea, gastrointestinal problems and anxiety. Nurses caring for children at end of life need to be able to assess and identify these physical and psychological concerns, and collaborate with the multidisciplinary team to alleviate these. Research into the effectiveness of management strategies is still needed in paediatric end-of-life care.

- Depending on their development and understanding, children and young people may wish to discuss their fears and worries about dying, and adolescents may like to be involved in advance care planning conversations. The skills to facilitate such conversations will develop with further specialised preparation and experience, and beginning paediatric nurses can observe more-experienced colleagues and increase their awareness of the communication skills used. Being a supportive presence and having a willingness to listen are valuable skills.

- Communication with the dying child’s family should be informative and sensitive, and provide family members with the opportunity to ask questions, be involved in planning care and management decisions, and disclose fears, concerns and emotions arising from caring for their dying child and their impending loss. Parents may feel isolated and unable to share their feelings with family, friends and even with each other as they struggle with their own feelings of grief. Siblings and grandparents will also need
Learning activities

12.1 Based on your reading in this chapter, what do you think are the main problems being experienced by our case study patient, Matthew? For each problem you identify, write down why this may be occurring for Matthew.

12.2 What strategies could you use to alleviate these problems for Matthew?

12.3 How would you involve Matthew and his family in your plan of care?

12.4 Communication is sometimes considered challenging for health professionals working with children and families in end-of-life care. What are some techniques you could use to facilitate effective communication in this situation? What are some of the barriers to effective communication in this context?

Further reading

Twycross, A & Stinson, J 2014, Physical and psychological pain relief methods in children, in A Twycross, S Dowden & J Stinson (eds), Managing pain in children: A clinical guide for nurses and health professionals, John Wiley & Sons, Chichester, pp. 86–99. This reading provides an overview of a variety of physical and psychological pain-relief strategies and current research evidence concerning their use in paediatric...
patients. It will provide you with a beginning understanding of pain-relief strategies and how they have been used effectively for children experiencing pain.

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Van Breemen, C 2009, Using play therapy in paediatric palliative care:


Youngblut, JM, Brooten, D, Blais, K, Hannan, J & Niyonsenga, T 2010, Grandparents’ health and functioning after a grandchild’s death, *Journal of*


| **Paediatric palliative care** – The multidisciplinary care of the child’s physical, psychosocial and spiritual needs, which encompasses the illness trajectory from diagnosis until death and includes end-of-life care. This care and support extends to the child’s family. |
| **Paediatric end-of-life care** – The multidisciplinary care of the child’s physical, psychosocial and spiritual needs, and the care and support of the child’s family at end-of-life and beyond |
| **Myoclonus** – Involuntary twitching that may occur when high doses of opioids are used, due to an accumulation of metabolites, which have neuro-excitatory effects |
| **Fatigue** – Feelings of tiredness and lethargy; a multidimensional term that includes physical, psychological, energy and sleep facets |
| **Dyspnoea** – Abnormal or difficult breathing that may include feelings of tiredness, suffocation, air hunger or panic associated with breathing, awareness of the work of breathing and chest tightness |
| **Cachexia** – The loss of appetite, weight and muscle mass that results from an underlying pathological condition, including those seen in palliative care |
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