Working with Young People

A Training Resource in Adolescent Health
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Introduction

Delivering health care to young people can be both challenging and rewarding. Many young people face complex health issues at a time when they are also developing new relationships and ways of dealing with the world. We now know that health problems arising in adolescence are likely to have implications for health in adulthood. We are, however, more confident than ever before that clinical interventions in adolescence can have both immediate and long term benefits for young people.

“Working with Young People” is a training resource that has been developed as an initiative of the Joint Adolescent Health Committee (JAHC) of the Royal Australasian College of Physicians (RACP) to help trainees develop the knowledge, skills and attitudes required to deliver effective health care to young people. It has specifically been designed in the context of the new RACP Basic Training Curricula (1) in Adult Internal Medicine and in Paediatrics and Child Health.

The training resource has been designed and written by Dr Jennifer Conn, a clinician and educator from The University of Melbourne. I gratefully acknowledge her expertise and dedication at every stage of the project.

I also wish to acknowledge the members of the JAHC for their oversight of the project. I would especially like to acknowledge the members of the JAHC working party, Dr Jenny Proimos, Dr Yvonne Bonomo and Dr Andrew Metz, who, together with co-opted members Dr Michele Yeo and Dr Lyndal Peake, contributed to the development of the educational materials.

The contributions of Professor Loane Skene, Dr Peter Simm and Associate Professor Agnes Dodds have extended the scope of the materials and brought a wide variety of expertise to the project.

I am most grateful to the trainees, Dr Andrew Metz, Dr Amy Gray, Dr Kumai Rajasegaran and Dr Ramin Shayan, and the young people who assisted with the development of the accompanying audio-visual material. I also wish to acknowledge the financial support of CSL Biotherapies (Vaccine Division) who funded the development of this material.

While the training package has been designed to help you gain an overview of the key areas of adolescent health and to address specific learning objectives from the Adolescent Health sections of the Basic Training Curricula, it is also designed to provide you with the skills to work with young people throughout your medical career. I hope that you enjoy working through the resource and that you also find working with young people highly rewarding.

Professor Susan Sawyer
Chair, Joint Adolescent Health Committee (2003-2008)
Royal Australasian College of Physicians
How to Use This Training Resource

“Working with Young People” is a training resource that has been designed around six key topics in adolescent health. It begins with an overview of adolescent development from a bio-psycho-social perspective before going on to explore ethico-legal issues relevant to caring for young people. Other topics cover therapeutic engagement, psycho-social assessment and the promotion of self-management in chronic illness. The final topic examines the issues surrounding transition to adult health care.

The content of each topic is based on a set of learning objectives that relate to the core knowledge, skills and attitudes required to effectively work with young people in a health care context. The material is designed to support the Adolescent Health sections of the Basic Training Curricula for Adult Internal Medicine\(^1\) and Paediatric and Child Health\(^2\).

Each topic includes text that is intended to provide an overview of the subject matter. This is supplemented by two readings that allow for deeper exploration of the topic. A list of additional readings is included at the end of each section for trainees who wish to further explore the topic. Charts for the measurement of growth, pubertal status and blood pressure are also included to assist with clinical skills development. An accompanying audio-visual resource in DVD format includes demonstrations by trainees of a selection of the clinical skills discussed in the resource.

Disclaimer:

The Joint Adolescent Health Committee of the Royal Australasian College of Physicians believes that the information contained in this training resource was accurate and reliable at the time of publication. The websites quoted in the resource were accessible at the time of publication, but The Royal Australasian College of Physicians can take no responsibility for the accuracy or future availability of these sites. The College, furthermore, cannot take responsibility for any adverse consequences that arise as a result of using the contents of this resource for clinical purposes. In particular, trainees and supervisors are advised to consult local laws and regulations pertaining to the delivery of health care to adolescent patients.

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\(^1\) Basic Training Curriculum: Adult Internal Medicine. Domain 2: Medical Expertise/Theme 2.5/Medicine throughout the lifespan/growth and development/Learning Objective 2.5.1: Manage common presentations in adolescents;

\(^2\) Basic Training Curriculum: Paediatrics and Child Health. Domain 2: Medical Expertise/Theme 2.5/Medicine throughout the lifespan/growth and development/Learning Objective 2.5.3: Manage common presentations in adolescents;
Topic 1: Adolescent Development

Learning Objectives
To be able to:

- discuss the definition of adolescence
- outline the burden of illness in the adolescent age group
- describe normal physical, cognitive and psycho-social adolescent development
- differentiate between the developmental stages of early, mid and late adolescence

Reading Material
The Definition of Adolescence

Adolescence is the stage of physical, cognitive and psycho-social development that takes place between childhood and adulthood. The onset is typically marked by the biological changes of puberty, whereas various social transitions help to define its conclusion. These social transitions are highly sensitive to prevailing cultural influences. In the past, milestones such as marriage and starting a family were reached in the late teens or early twenties, whereas these days many young people are still engaged in higher education or establishing their vocation at this age and establishing a family unit is often delayed until at least a decade later. This has resulted in the end of adolescence becoming less distinct.


For epidemiological purposes, the World Health Organisation defines adolescence as the period of life between the ages of 10-19 years and ‘youth’ as the period between 15-24 years. It combines these age groups and assigns the term ‘young people’ to those between 10-24 years. These classifications are widely applied but other definitions are also used. The Australian Institute of Health and Welfare, for example, defines ‘young people’ as those aged between 12-24 years. Because adolescence spans such a wide age range and encompasses diverse and complex developmental changes, it is often divided into three sub-stages: early adolescence (10-14 years), mid-adolescence (15-17 years) and late adolescence (>17 years).

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The Burden of Illness in the Adolescent Age Group

Most adolescents are healthy and contented and negotiate the transition to adulthood without difficulty. Others however, suffer from significant physical or psychological morbidity, with approximately 15-20% of adolescents having some type of special health care need. Children and young people with special health care needs are defined as:

"... those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

Many health problems in young people have a psycho-social rather than a biological basis. These problems typically arise as a consequence of risk-taking behaviours or difficulties negotiating the developmental challenges of adolescence. Accidents and injuries, either self-inflicted or unintentional, and behavioural problems, such as substance abuse and unsafe sexual experimentation, account for most of the morbidity and mortality in this age group. This highlights that preventable issues constitute much of the morbidity and mortality in this age group.

Mental health problems account for about 50% of the burden of illness in adolescence, with up to 20% of young people being affected at some time during this period. Some mental health problems are mild and transitory. Others, such as attention deficit hyperactivity disorder, will have continued into the adolescent years from childhood. Yet others represent the beginning of psychopathologies that will persist into adulthood. Schizophrenia, for example, has its peak onset during late adolescence and early adulthood. Anxiety and depression are common in young people, with these conditions being the leading causes of mental disorders in young Australians aged 15-24 years in 2003. Eating disorders are also common in the adolescent age group, particularly in females.

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Chronic disease also contributes to the burden of illness in the adolescent age group. The most common chronic conditions in young people are respiratory illnesses, such as hayfever and asthma\(^{10}\). While there is some evidence that the prevalence of asthma has plateaued in Australia, the overall burden of chronic illness in adolescence continues to be significant. There has been an increase in the incidence of conditions such as type 1 diabetes mellitus, obesity and Crohn’s disease\(^{11,12}\), and partly by increased survival rates from a number of childhood diseases, such as leukaemia, cystic fibrosis and congenital heart disease\(^{13}\). In addition, health care in this age group has become more complex with greater dependence on advanced technologies, such as insulin pump therapy for type 1 diabetes mellitus.


An Overview of Adolescent Development

The developmental changes that take place during the adolescent years have important implications for doctors involved in the health care of young people. Not only is it important for clinicians to monitor the physical, cognitive and psycho-social development of the adolescent patient, but it is also necessary to have an appreciation of the young person’s developmental level for optimal therapeutic engagement\(^\text{14}\). Health care professionals can also play an important role in supporting young people’s growing autonomy from their parents and helping them to take greater responsibility for their own health care.

Physical development during adolescence is characterised by the pubertal growth spurt and the associated endocrine changes that lead to the acquisition of reproductive potential. Other organs and body systems, in particular the brain, also undergo maturation during this time. Cognitive maturation results in an increased capacity for abstract thought, with young people becoming increasingly able to engage in hypothetico-deductive reasoning and to anticipate and evaluate the consequences of their actions.

During adolescence, young people also begin to acquire a strong personal identity, separate from their family, as a result of the interplay between their growing intellectual capacity and their broadening social interactions. They typically develop a clearer sense of their own beliefs and values, and take greater responsibility for their own thoughts and behaviours. The consolidation of personal identity enables young people to set realistic vocational goals and to form mutually-sharing intimate relationships.

Physical Development

The onset and rate of progression of maturation in adolescence varies enormously between individuals. This can generate considerable anxiety as most adolescents wish to conform to group norms rather than be different from their peers. Asynchronous development between domains within an individual may also occur, which can have a significant impact on the young person’s physical and psychological well-being.

Adolescence is a period of development marked by rapid changes in body size, shape and composition. With maturation of the neuroendocrine axis, the pubertal growth spurt occurs and secondary sexual characteristics begin to develop. These changes are associated with dimorphic alterations in the relative proportions of water, muscle and fat as well as the acquisition of reproductive capacity. Boys become taller and develop a more muscular physique, which is accompanied by testicular development and enlargement of the penis. Girls acquire a rounded female shape and display outward signs of breast development, followed by the onset of menstruation. Other body systems also undergo maturation. Changes in the cardiovascular system, for example, include an increase in aerobic power and blood pressure and alterations in blood lipids. During this time the adolescent brain matures, a process that continues into young adulthood.

The Adolescent Growth Spurt

In early adolescence, growth rapidly accelerates under the influence of the growth hormone-insulin-like growth factor and thyroid axes. There is wide variation in the timing of this growth spurt, with genetic, psychological and social factors all playing a role. The timing is also gender specific, with peak velocity typically occurring two years earlier in girls than boys. Males, however, achieve a greater adult height on average than females because they are older, and therefore taller, when they enter puberty, and have a greater peak height velocity and a longer growth spurt.

In early adolescence, growth predominantly takes place in the distal regions of the limbs, with acceleration in the proximal limbs occurring later in puberty. This asynchronous growth can make the adolescent appear gangly and awkward. By mid-adolescence, 95%

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of adult height will have been achieved. Growth at this stage will be largely truncal rather than peripheral. By late adolescence, growth is virtually complete and the young person’s proportions will have levelled out.


Adolescent growth is monitored using standardised growth charts. The National Health and Medical Research Council (NHMRC) clinical practice guidelines recommend that the Centres for Disease Control (CDC) 2000 growth curves be used in the clinical setting. A set of these charts, designed for use in Australian and New Zealand settings, is included at the end of this section. These charts can also be downloaded from the Australasia Paediatric Endocrine Group (APEG) or CDC websites21,22.

Sexual Maturation

In late childhood, a complex series of biological events takes place, triggered by the central nervous system, in particular the hypothalamus and the pituitary gland, which lead to the transformation of the physically immature child into an adult capable of reproduction. The onset of these pubertal changes typically occurs between the ages of 9-13 years for girls and 10-14 for boys.

The first evidence of sexual maturation in girls is the development of breast buds, while in boys it is an increase in the size of the penis and testes. In both sexes, pubic hair starts to appear. At this stage, reproduction is usually not possible. As puberty progresses, girls start to menstruate and boys experience the first emission of semen, usually as wet dreams. By mid-adolescence, the development of secondary sex characteristics is typically well advanced. Other changes, such as acne, body odour, voice change and moodiness will also be noted. Menstruation in girls is established and fertility is possible. By late adolescence, reproductive changes are virtually complete. The sequence of development of secondary sexual characteristics is linear and predictable and has been staged by Marshall and Tanner23,24. They described five categories, with the first stage representing pre-pubertal morphology and the fifth stage being adult development. These stages are illustrated in the growth charts on the APEG website.

21 www.apeg.org.au
22 www.cdc.gov
Most adolescents progress through sexual maturation without complication. Delayed puberty and short stature can generate considerable anxiety and impact on self-esteem, especially in boys. The underlying cause is usually constitutional delay, often with a familial basis. Delayed puberty, however, can be a sign of an underlying pathological condition. In boys, testicular volume is a useful indicator of development and can be assessed using a Prader orchidometer. Referral for further investigation is warranted if by age 15 a boy has a testicular size of less than 4 ml. Likewise, in girls, further assessment should be initiated if there has been no breast development by age 13.5 or if menstruation has not commenced by age 15. Earlier referral may be indicated if the young person with delayed puberty is struggling to cope with being different from their peers.

Precocious puberty is less common than delayed puberty. It can be a normal variant or due to a wide range of pathological conditions, such as endocrine diseases or central nervous system tumours. Breast development starting younger than 8 in girls or signs of puberty before the age of 9 in boys should generate cause for concern. Early pubic hair development in the absence of breast or testicular enlargement is a sign of premature adrenarche rather than a sign of true precocious puberty. Girls younger than 7 and boys younger than 8 with signs of adrenarche require investigation for underlying causes. Growth velocity is an important clinical parameter in these patients. Children with true precocious puberty or a pathological cause of adrenarche often have accelerated growth velocity.

**Brain Maturation**

Historically, it was believed that the brain was fully formed by the end of childhood. Research made possible by advances in brain imaging technology has provided evidence that adolescence is in fact a period of profound brain growth and change. It has become clear that brain connections and signalling mechanisms selectively change during the teenage years, especially with respect to behaviour and emotion, and that these changes continue into young adulthood.

Some of the most important changes that take place in the adolescent brain occur in the frontal lobes, especially in the pre-frontal cortex, the region responsible for organisational ability, strategic thinking and impulse control. At the start of puberty, thinning of the grey matter of the frontal lobes occurs as the brain prunes redundant synapses and becomes more efficient. This is accompanied by an increase in myelination, leading to enhanced speed and distance of neuronal signalling. Dopamine inputs to the pre-frontal cortex also

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26 Prolong FP, Crowley WF. Diagnosis and treatment of delayed puberty. UpToDate 2008;18.3.
increase dramatically and may contribute to the development of mature judgement and impulse control during adolescence. Age-related changes have also been observed in other areas of the cortex and in subcortical structures such as the corpus callosum.\textsuperscript{28}

The relative importance of genetic and environmental factors in influencing brain development in adolescence is yet to be established. It is known that gonadal hormones influence a wide range of neuronal activities and may account for gender differences in brain development during this period.\textsuperscript{29} Stress during puberty may impact on the development of the brain and its vulnerability to mental illness.\textsuperscript{30} The adolescent brain, particularly the pre-frontal cortex and the hippocampus, is also vulnerable to the effects of alcohol.


Cognitive Development

Of the many changes that take place during adolescence, one of the foremost is the shift in cognitive functioning from concrete to formal operational or abstract thought. During adolescence, young people become increasingly able to use symbols to represent objects from reality and to articulate concepts that do not have concrete representation. This process occurs as a result of brain maturation, shaped by interaction with the psycho-social environment. Cole et al have described four specific characteristics of abstract thought that, according to developmental psychologists, distinguish adolescent thinking from that of younger children31.

Table 1.1: Specific Characteristics of Adolescent Thinking

- Hypothetico-deductive reasoning
- Planning ahead
- Metacognition
- Thinking beyond conventional limits

During adolescence, young people become increasingly able to use hypothetico-deductive reasoning for problem solving. They can generate multiple hypotheses for a given situation and mentally test the competing options in a logical fashion. This has important implications in the health care setting, especially in relation to medical decision making. In late childhood and early adolescence, decision-making ability will be limited, and substantial input from parents into the young person’s medical care will generally be required. By mid-adolescence, young people will be more capable of making choices about their health care, although this raises complex ethical and legal issues. These will be explored in Topic 2. By late adolescence, decision-making skills will usually be highly developed, with young people being able to systematically and independently evaluate the various treatment options open to them.

With the development of abstract thought, young people also become more able to think in a longer time frame, or plan ahead, than they did in childhood. As their concept of time reaches maturity, young people can visualise the future and start making decisions in a more strategic manner. During late childhood and early adolescence, however, a young person may have difficulty appreciating the effects of current behaviour on long term health. As a consequence, management plans and preventative strategies need to be framed in the short term, with instructions requiring frequent repetition. By mid-adolescence, young people will be more skilled at evaluating the potential impact of their current actions, not only in interpersonal settings, but also with respect to their future health, although this will

be variably applied. At this stage, delivery of information to young people still needs to focus on the short to medium term, with preventative health messages being tailored accordingly. A young person at this level of development will, for example, relate more to a discussion about the adverse cosmetic effects of smoking than to one about its long term consequences, such as lung cancer or vascular disease. By late adolescence, young people typically have a clearer perspective of the future and will be more likely to engage in preventative health measures.

During adolescence, young people develop the ability to think about thinking, a process known as metacognition. This enables young people to deliberate on the successes and failures of their decision making and to modify their thoughts and actions on the basis of their experiences. They also become able to process memories and perceptions in a more sophisticated manner, leading to greater self reflection. Metacognition can be used to develop strategies such as mnemonic devices that can assist learning. Asking young people to analyse their cognitive processes can be a helpful strategy for promoting self-management in the setting of chronic illness.

Young people during adolescence also develop the ability to think beyond conventional limits. They acquire the mental capacity to reflect on important philosophical issues, particularly those relating to morality, politics and spiritual development, including non-physical interpretations of death. This type of thinking is often accompanied by idealism, which can generate conflict as the young person becomes critical of what they see as the hypocrisies of the adults around them. The desire for a perfect world often motivates young people to seek out heroes with whom they can identify. A young person with a chronic disease, for example, may be inspired by a sporting idol who is living with the same illness.

The development of abstract thought occurs at a variable rate. The assessment of a young person’s cognitive level in adolescence can be challenging in the clinical setting, especially when development in other domains is asynchronous. Blum and Stark have suggested that the capacity for abstract thought can be tested by producing a hypothetical scenario and asking the young person to identify and weigh up the various options that exist for that situation. Another way is to ask about vocational goals. A young person who is still a fairly concrete thinker will often provide unrealistic options, such as wanting to be an astronaut as well as a brain surgeon, and be unable to say how they might achieve this ambition. It is important to remember that under the stress of illness a young person who has achieved formal operational thought may retreat to an earlier level of functioning.

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33 Huebner A. Adolescent Growth and Development: Available at: www.ext.vt.edu/pubs/family/350-850/350-850.html
Psycho-Social Development

Although the development of an integrated sense of self is a lifelong process, many key aspects of identity are forged during adolescence\(^ {36} \). Identity formation involves developing an appreciation of one’s unique set of physical and psychological characteristics, as well as building a secure sense of self with respect to gender, sexuality, and ethnicity. The formation of a stable identity occurs through interaction with the surrounding social environment and involves the development of not only a sense of uniqueness but also of connectedness with others\(^ {37} \).

With the rapid physical changes that occur at puberty, it is not surprising that one of the most significant components of identity formation, especially in early adolescence, revolves around body image and personal appearance. Young people at this time are very focused on their bodies and whether their physical development is progressing along the normal trajectory. Having a different rate of development from age-matched peers can generate significant stress in young people. Negative feelings about body image can also be a source of low self-esteem and depression, which can lead to maladaptive behaviours, such as erratic food intake and dieting. These in turn may lead to significant health issues, such as poor nutrition and eating disorders. Doctors can play an important role by actively providing reassurance about normal development, especially during physical examinations. By mid-adolescence, concerns about the physical changes of puberty generally diminish and the focus shifts to grooming and physical presentation. By the end of adolescence, young people are typically more comfortable with their body image.

As their capacity for abstract thought develops, young people also begin to think about how others perceive their personal characteristics. This, however, can result in excessive self-consciousness. In early adolescence, young people are typically very egocentric and tend to believe that everyone else is as aware of their appearance, thoughts and behaviours as they are themselves. Child psychologist David Elkind called this the “imaginary audience”\(^ {38} \). He linked this with the sense of uniqueness that many young people in early adolescence experience, which he called the “personal fable”. This, he argued, can make young people think that no one else experiences the feelings that they do and that no one understands them.

As young people move into mid-adolescence, their expanded cognition and greater life experience allows them to articulate more clearly their own distinctive set of skills and personal qualities\(^ {39} \). As they strive for a more defined identity, most young people in this

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age group become more experimental in their behaviour. A certain amount of risk-taking is a normal aspect of healthy adolescent development but many young people engage in behaviour that places them at significant danger of physical and psychological harm. There is growing evidence that young people’s perception of risk, and their sense of vulnerability to it, is as well-developed as that of adults, but that psycho-social immaturity and contextual factors contribute to poor self-regulation. Psycho-social factors over-ride cognitive control networks at times of high emotional arousal or under the influence of peer groups. It is hardly surprising that most risk-taking behaviour in adolescence takes place in groups, or that experimentation with drugs, alcohol and unsafe sex usually peaks during mid-adolescence at a time when there is maximum mismatch between young people’s logical reasoning skills and psycho-social maturity. Unfortunately risk-taking behaviour during this time, such as the consumption of excessive amounts of alcohol, has the potential to cause long lasting and irreversible effects.

By late adolescence, young people will usually have a more established sense of their own identity and place in society. They will be more able to understand the consequences of and to regulate their own behaviour, and will have a more well developed ethical and moral value system. Adolescents should, by this time, have established a healthy balance between their aspirations, fantasies and reality. By late adolescence, young people typically will have a clearer idea about their role in society and will have set realistic goals for life, with workable plans about how to achieve them.

The development of a secure sense of one’s gender and sexuality is also an important component of identity formation. In early adolescence, the development of secondary sexual characteristics focuses young people’s thoughts on what it means to be male or female. Gender role conformity is very strong during this phase. As young people continue to develop, they become increasingly aware of themselves as sexual beings with a sexual orientation and sexual desires. By mid-adolescence, sexual identity starts to mature, and sexual drives and romantic fantasies emerge. This can be a very confronting time for young people with same-sex and bisexual orientation. Pressure to conform to societal norms may cause significant psychological distress in gay and lesbian young people, with many having a fear of rejection if they disclose their sexual orientation to family and friends. By late adolescence, gender role and sexual orientation are essentially secured.

### Table 1.2: Psycho-Social Development Across Adolescence

<table>
<thead>
<tr>
<th></th>
<th>Early adolescence</th>
<th>Mid-adolescence</th>
<th>Late adolescence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body image</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Focus on bodily changes of puberty</td>
<td>- Less concern about changes of puberty</td>
<td>- Realistic body image</td>
<td></td>
</tr>
<tr>
<td>- Anxiety about normality</td>
<td>- Focus shifts to appearance</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Psychological identity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Self-conscious and egocentric</td>
<td>- Personal qualities appreciated in abstract terms</td>
<td>- Sense of identity more established</td>
<td></td>
</tr>
<tr>
<td>- Sense of uniqueness</td>
<td>- Increase in risk-taking behaviour</td>
<td>- Ethical and moral value system developed</td>
<td></td>
</tr>
<tr>
<td>- Vocational goals often not realistic</td>
<td>- More realistic vocational goals</td>
<td>- Working towards vocational goals</td>
<td></td>
</tr>
<tr>
<td><strong>Gender, sexual and cultural identity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Focus on secondary sex characteristics</td>
<td>- Sexual identity develops</td>
<td>- Gender role and sexual orientation usually secure</td>
<td></td>
</tr>
<tr>
<td>- Gender role conformity strong</td>
<td>- Sexual drives increase</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Romantic fantasies</td>
<td>- Issues relating to cultural identity important</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Autonomy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Emotional separation from parents commences</td>
<td>- Search for greater autonomy and privacy within family unit</td>
<td>- More autonomous</td>
<td></td>
</tr>
<tr>
<td>- Desire for greater privacy</td>
<td>- Family conflicts</td>
<td>- Increasing financial independence</td>
<td></td>
</tr>
<tr>
<td><strong>Social relationships</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Same-sex friendships predominate</td>
<td>- Strong need for peer acceptance</td>
<td>- Less influenced by peers</td>
<td></td>
</tr>
<tr>
<td>- Contact with opposite sex in group settings</td>
<td>- Dating and sexual activity more common</td>
<td>- One-to-one relationships more important</td>
<td></td>
</tr>
</tbody>
</table>
Establishing a strong ethnic or cultural identity is another important element of identity formation in adolescence, especially for young people from minority migrant groups\textsuperscript{45}. This may cause conflict for those trying to fit into a dominant culture, although for many such young people it can help to create a strong sense of personal identity. For those from the ethnic majority, ethnic identity formation may involve forging a sense of self in a multicultural society\textsuperscript{46}.

With the emergence of a strong sense of personal identity comes a shift towards greater autonomy and self-reliance. In early adolescence, young people start to forge an identity separate from their family. They begin to make decisions independently and in general become more confident in their ability to do so successfully. Young people at this level also start to develop independent attitudes and beliefs about politics, spirituality and moral values. Tensions may arise between young people and their families over assertions of autonomy, and this is often associated with conflict, mainly over minor issues such as domestic chores. There is also often a desire for greater privacy within the family unit. Although relationships remain very family focused at this age, young people increasingly turn to peers for social activities. Same-sex friendships predominate and contact with the opposite sex occurs usually in group settings.

By mid-adolescence, young people will typically take on more responsibility within the family unit and be more accountable for the consequences of their behaviours. Family conflicts about emerging independence may intensify and young people can become more aggressive in their search for greater autonomy and privacy. Young people in this age group usually have a heightened need for acceptance by their contemporaries. Peer groups can exert considerable influence on individuals, and this in turn can have a powerful effect on mental status, either in a positive or negative fashion. With the emergence of a sexual identity, dating and sexual activity become more frequent, although relationships tend to have a narcissistic quality\textsuperscript{47}. Studies suggest that up to 50\% of Australian teenagers have engaged in sexual intercourse by age 16\textsuperscript{48}.

The influence of peer group and family typically diminishes in late adolescence in favour of one-to-one intimate relationships. With the consolidation of personal identity, relationships become more mutually-sharing in quality. Young people become more socially autonomous as they develop their educational and vocational capacities and move towards financial independence.\textsuperscript{45,46}

\textsuperscript{46} Frankel L. Identity Formation in Adolescence. New York: ACT for Youth; 2002. Available at www.actforyouth.net
independence. Their greater sense of personal responsibility will be reflected in the ability to take charge of their own health care, although many, especially those with chronic illnesses, will still value and benefit from input from their parents.

**Clinical Tasks:**

Talk with three young people, each from a different stage of adolescent development. Choose young people who do not have any significant health issues. Compare and contrast the information that you obtain.

Talk with young people from each of the following developmental stages:

- late childhood or early adolescence (9-11 years)
- mid-adolescence (15-17 years)
- late adolescence or early adulthood (18-24 years).

Complete the following tasks, adapting your instructions to match the developmental level of the young person:

(i) Ask the young person about their vocational goals and how they plan to achieve them.

(ii) Ask the young person about their leisure activities and social networks.
(iii) Ask the young person about their perceptions of their body shape.

(iv) Find out what qualities the young person values in a doctor.

*Australian and New Zealand Growth Charts. Boys 2 – 18 years and Girls 2 – 18 years. Pfizer Australia.*
Further Reading

Journal Articles


Books


Websites


Topic 2: Ethical and Legal Issues

Learning Objectives

To be able to:

- discuss ethical and legal principles surrounding privacy and confidentiality in adolescent health care
- apply these principles when dealing with adolescent patients
- describe state-specific legislation with respect to consent in adolescent health care
- assess cognitive ability and maturity of an adolescent in regard to decision making and consent to treatment

Reading Material


Privacy and Confidentiality in Adolescent Health Care

The ethical principle of confidentiality lies at the very core of the doctor-patient relationship. When individuals seek medical care, they have the right to expect that their medical concerns will not be divulged to others. The trust that arises from this encourages patients to freely provide the information, often of a highly sensitive nature, required for doctors to establish accurate diagnoses and to provide optimal treatment. This principle raises important implications for those involved in the provision of health care to young people under the age of 18. At the beginning of adolescence parents are, for the most part, responsible for a young person’s health care. During the following years, young people gradually acquire an increased capacity for decision-making and for taking responsibility for their own health. This is typically accompanied by a desire for greater privacy, a concept that the law now recognises.

Why is confidential health care for adolescent patients important? Evidence suggests that concerns about confidentiality can act as a barrier to accessing health care for the adolescent, particularly for issues relating to sexual activity, mental health and substance abuse. Young people are more likely to seek health care and return for review if they know that their health concerns will not be revealed to their parents or other third parties. One study showed that 60% of adolescents would stop using sexual health services or delay seeking testing or treatment for sexually transmitted infections if their parents were notified. Another study showed that 17% of adolescents report having foregone health care because of concerns about their parents finding out. Research has also demonstrated that confidential health care promotes disclosure by young people about behaviours that entail health risk. It is therefore evident that the majority of adolescents wish to obtain health care for some, or all, of their health concerns without parental knowledge.

Although confidentiality is an ethical right for the adolescent patient who is sufficiently mature to make his or her own medical decisions, certain exceptions exist. These are broadly similar to those for adult patients. A doctor may divulge information to a third party if an adolescent patient has given consent for information to be given to that person. This

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7 www.privacy.gov.au/privacy_rights/laws
consent may be written or implied, but it is important that the young person has not been pressured into giving it. Confidentiality may also be breached in the case of an emergency where information transfer is critical for the well-being of the patient.

Another exception to the duty of confidentiality, which is of particular relevance in adolescent health care, applies when the young person is at risk of significant self-harm or is at serious and imminent risk of harming others. An exception also applies if the young person is the victim of, or is at risk of, physical, emotional or sexual abuse. In these circumstances, mandatory reporting applies in all states except for Western Australia, although legislation is currently being developed to bring the latter into line with the other states\(^8\). The age at which mandatory reporting applies varies across Australasia\(^9,10\), as does the age of consent for intercourse, which may be relevant in cases of suspected sexual abuse\(^11,12,13\). Other statutory or mandatory exceptions that may apply to the duty of confidentiality include court proceedings, notifiable diseases such as sexually transmitted infections, pandemic influenza or food poisoning, and blood testing of drivers for alcohol and drugs.

**Table 2.1: Summary of Exceptions to the Duty of Confidentiality**

1. The young person consents to disclosure
2. The young person is at risk of harm or harming others
   - Risk of significant self-harm
   - Risk or victim of physical, emotional or sexual abuse\(^*\)
   - Imminent risk of harming others
3. Legal requirement for disclosure
   - Court proceedings
   - Notifiable diseases
   - Blood testing for alcohol or drugs
4. Necessary for young person's well-being
   - Urgent communication in emergency
   - Communication within a team

\(^*\) See state specific regulations for mandatory reporting

In recognition of their right to privacy, Medicare Australia will provide a separate Medicare card from their family to young people when they turn 15\(^14,15\). A doctor can bulk bill in these circumstances without informing the young person's parents. Adolescents can obtain their

\(^{9}\) ibid.
\(^{10}\) www.electiveservices.govt.nz/guidelines/adolescent-sexual-abuse.html
\(^{11}\) www.afao.org.au/library_docs/policy/Age_of_consent_briefing_paperJune06.pdf
\(^{12}\) www.alrc.gov.au
\(^{13}\) www.newzealand.govt.nz
\(^{14}\) www.medicareaustralia.gov.au
\(^{15}\) Note that there is no equivalent to Medicare in New Zealand.
own card if they are younger than 15 and their parents request that they be provided with one. Medicare Australia will also issue a card to an adolescent less than the age of 15 if it is deemed appropriate for other reasons, such as when protective services are involved with the young person. Parents cannot obtain information about their child’s Medicare claims history after the young person has turned 14. Medicare Australia requires the explicit consent of the young person before divulging such information.

According to law, a young person has the same right of access to their medical records as an adult\textsuperscript{16}. Such a request may not be granted if the clinician involved feels the information may have a detrimental effect on the young person. If this is the case, the records may be made available to the young person’s doctor or another doctor so they can explain the information to the young person. Parents have only a limited right to obtain access to their child’s medical records when it is necessary for them to make medical decisions for the child. Once an adolescent patient is deemed competent, he or she can refuse parental access to their medical records.

The Australian Law Reform Commission recently reviewed the Privacy Act to provide statutory clarity with respect to privacy of information, including health information for young people under 18\textsuperscript{17}. The government has yet to agree to these recommendations.

\begin{quote}

Available from: www.mja.com.au
\end{quote}

\textsuperscript{16} www.privacy.gov.au/privacy_rights/laws
\textsuperscript{17} see www.austlii.edu.au/au/other/alrc/publications/reports/108/
Applying Privacy and Confidentiality in Adolescent Health Care

Confidentiality needs to be discussed with all adolescents at the beginning of the medical interview. This involves checking if the young person understands the meaning of confidentiality and then briefing them about their rights. The concept of team confidentiality should be explained to a young person whose health care is being provided in a multi-disciplinary setting.

Briefing a young person about confidentiality also involves addressing the ethical and legal limits on confidentiality. This should include the need to breach confidentiality if a young person is deemed to be at risk of harming themselves or another person, or if they are, or are at risk of, being harmed by someone else. It may also be appropriate to discuss confidentiality again later in the interview prior to broaching a sensitive topic.

It is also important to educate the young person’s parents about the concept of confidentiality. The discussion needs to emphasise that privacy in adolescent health care is standard practice and should be framed in the context of the young person's personal development. Most parents will welcome this explanation, but it is essential to be aware of cultural sensitivities. The duty of confidentiality does not preclude encouraging and empowering young people to talk about important issues relating to their health and well-being with their parents. Just because young people reach the age at which they should be seen alone for part of a consultation does not reduce the value of parental contribution to consultations. The challenge is to engage with young people as well as parents in ways which are appropriately respectful of each.

When the confidentiality of a young person needs to be breached, it is critical to involve them in the process. Explore the reasons why they do not want their family to know about their current situation. Help them to work towards telling their parents or offer to help them do so. Make it clear that not all the information that they have given you needs to be shared with their parents. Regard all information as confidential until discussion and negotiation has taken place. As a registrar, always discuss with your consultant any concerns that you may have about the safety of an adolescent patient.

At the conclusion of a consultation, always ask the young person about the best way to contact them if follow up is required. This can help to avoid accidental breaches of confidentiality.

Finally, the duty of confidentiality applies not only to the medical interview but also to the documentation of the young person’s medical assessment. If the young person has asked you to keep certain information private, record this clearly in your notes. It may be helpful to head the relevant page with a warning that it contains confidential information.
**Case Study 2.3**

Rebecca, 18, has type 1 diabetes mellitus and has been admitted to hospital with diabetic ketoacidosis. She lives at home with her parents and is currently studying law at university. Her parents have always been closely involved with her medical care. You take a telephone call on the ward from her father who requests information about her test results and the precipitating factor for her current illness.

(i) What is your duty of confidentiality to Rebecca?

(ii) How would you approach the telephone conversation with her father?

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**Case Study 2.4**

Erik, 17, has been admitted with alcohol intoxication. He has had the same general practitioner since he was a young child and has listed this doctor in the hospital data base. You are in the process of preparing the discharge summary. Erik asks that no information about his admission be passed on to his general practitioner.

(i) What is your duty of confidentiality to Erik?

(ii) How would you manage this scenario?
Case Study 2.5

Rani, 14, has asthma and has been admitted with a chest infection. During your initial assessment, she reveals that her mother’s new boyfriend sometimes touches her when they are alone together in ways that make her feel embarrassed. She immediately says that she wished that she hadn’t told you that. She then refuses to allow you to pass this information on to anyone else.

(i) What is your duty of confidentiality to Rani?

(ii) How would you manage this scenario?

Case Study 2.6

Tim, 13, has been brought by his father to the Emergency Department with acute gastroenteritis. When his father steps out to buy coffee from the hospital café, Tim mentions that he has been taking amphetamines with some older friends at school. He doesn’t want you to tell anyone about this, especially his father.

(i) What is your duty of confidentiality to Tim?

(ii) How would you manage this scenario?
Case Study 2.7
Jack, 14, has returned for review of his epilepsy. His last seizure was three months ago. While his parents are out of the room, he reports that he gained weight and felt irritable on his medication and stopped taking it. He doesn’t want to take any other medications for his epilepsy and doesn’t want you to tell his parents.

(i) What is your duty of confidentiality to Jack?
(ii) How would you manage this scenario?

Case Study 2.8
Nadia, 15, has been treated for Hodgkin’s disease and has returned for routine follow up. During the physical examination, you note that she has been cutting herself on her forearms. She says that her parents aren’t aware that she has been doing this and she doesn’t want you to tell them.

(i) What is your duty of confidentiality to Nadia?
(ii) How would you manage this scenario?
Clinical tasks:

Talk with young people about their thoughts with regard to confidentiality in health care.

Practise briefing young people about confidentiality in the health care setting.
**Consent in Adolescent Health Care**

Physicians are required by law to obtain informed consent prior to initiating medical treatment\(^\text{18}\). Valid informed consent requires the patient to be competent and to give their consent voluntarily. Under Australian and New Zealand law, a person over the age of 18 is legally entitled to make decisions about their health care if they have the capacity to do so. A parent or guardian can make decisions on behalf of a child under the age of 18, although the law recognises the right of a minor to make their own decisions if they are deemed to be sufficiently mature. This is of particular significance in situations where there is conflict between parent and child or if a young person does not wish details of their medical treatment to be divulged to their parents.

The right of adolescent patients to consent to their own medical treatment was set by legal precedent in the mid 1980s in a case in the English House of Lords by Gillick v West Norfolk and Wisbech Area Health Authority\(^\text{19}\). In this landmark case, Victoria Gillick sought a court order that it was not lawful for medical practitioners to prescribe contraceptive treatment to minors younger than 16 without their parents’ knowledge or consent. In its ruling, the Court recognised that parental authority to consent to the medical treatment of their child diminishes as the young person’s capacity to understand and make decisions about the proposed treatment grows.

A young person’s right to consent to medical treatment was endorsed as part of common law by the High Court of Australia in Marion’s Case\(^\text{20}\). This case involved a 14-year old intellectually disabled girl with epilepsy whose parents wished her to have a sterilisation procedure. The ruling was that Marion’s parents could not decide on their own to have their daughter sterilised. An authorisation from a court, usually the Family Court, would be required for such a major medical intervention. The Court also took the opportunity to review the law on medical procedures for young people in a broader sense. The case established the principle that the courts could act as referees in disputes between parents and children and, where relevant, in disputes with medical practitioners about proposed treatment plans.

While the Gillick case upheld the right of a young person to consent to medical treatment, it did not as a corollary confer the right to refuse treatment. It is possible for parents or the courts to override a decision made by a young person under the age of 18, if it is judged to be in their best physical or psychological interest. In practice, however, most doctors would feel very uncomfortable about forcing a young person to have treatment against their will.

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\(^\text{18}\) Appelbaum PS. Assessment of Patients’ Competence to Consent to Treatment. NEJM 2007; 357:1824–1840.
\(^\text{19}\) Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402 (HL).
\(^\text{20}\) Secretary of the Department of Health and Community Services v JWB and SMB, (1992) 175 CLR 218.
Assessment of Cognitive Ability and Maturity for Consent

To give informed consent to a medical procedure, a patient must be able to understand what the treatment involves, what it is for, why it is needed and why it applies to them as an individual. He or she must also appreciate the risks associated with the treatment and be aware of the other options available, as well as the consequences of not pursuing treatment. For an adolescent patient, the capacity to give informed consent is closely linked to their stage of cognitive development, in particular their capacity to participate in hypothetico-deductive reasoning. There is no fail-safe way to determine if an adolescent patient has the intellectual ability or maturity required to give consent to a medical treatment. Such an assessment is highly complex and contextually dependent.

The age of the patient can be used as an approximate guide although it is not always reliable. Any young person over the age of 18 is considered to be an autonomously functioning adult in the eyes of the law. Authorities would also regard most young people over 16 as being able to make informed decisions about their medical care. Young patients under the age of 14 will, in general, not be able to give consent independently, although this does not mean that their wishes cannot be taken into consideration.

The issue is less clear cut for young people between 14 and 16\textsuperscript{21}. Other factors need to be considered such as the statutory and legal context, level of schooling, decision-making ability in other areas and cognitive capacity, especially with respect to hypothetico-deductive reasoning. The young person’s mental status also needs to be taken into account although the presence of a psychiatric condition or an intellectual disability does not necessarily preclude giving consent. It is also important to remember that psychiatric conditions fluctuate over time so a decision made about a young person’s ability to give consent at one point in time may not apply at a later date.

Family context is an important factor to consider when deciding whether a minor is capable of giving consent for treatment. A young person living independently from their family may be judged more capable of decision making in a medical situation than one who is still living with their parents. This may also apply if the family cannot act in a supportive manner due to mental illness or substance abuse, although input from protective services will be required if there is any concern about the young person’s maturity. Cultural factors may also influence the level of family involvement in the decision-making process.

The degree of competence required also varies with the complexity of the proposed treatment. Starting the oral contraceptive pill, for example, is considered low risk compared with, say, having a termination of pregnancy, which would require a higher degree of ma-

\textsuperscript{21} Kuther TL. Medical decision-making and minors: issues of consent and assent. Adolescence 2003;38:343–358.
turity on the part of the young person. Very high risk procedures, such as gender reassign-
ment or sterilisation of an intellectually disabled adolescent, require Family Court involve-
ment; even parents cannot give consent in these circumstances.

The specific issue of provision of contraception to an adolescent was addressed by Lord
Fraser, one of the Law Lords responsible for the Gillick judgement. The Fraser Guidelines
state that for a health professional to lawfully provide contraceptive advice and treatment
to a young person without parental consent, the following criteria need to be met:

- the young person has understood the health professional’s advice
- the young person cannot be persuaded to inform their parents
- the young person is likely to begin, or to continue having, sexual
  intercourse with or without contraception
- the young person’s physical and mental health is likely to suffer unless
  contraception is provided
- the young person’s best interests require them to receive contraceptive advice
  or treatment, with or without parental consent

Although these guidelines refer specifically to contraception, the principles are helpful for
other situations where a young person wishes to obtain medical treatment without paren-
tal consent.

When making an assessment of a young person’s maturity with respect to consent, it is
important to meticulously document all the factors that have been taken into consideration.
A second opinion from another clinician is strongly advised in all but low risk situations. For
trainees, consent without parental involvement must always be discussed with a consult-
ant.

Medical Practitioners Board of Victoria. Consent for Treat-
ment and Confidentiality in Young People. Melbourne: Med-
ical Practitioners Board of Victoria; 2004.

Disclaimer: This article provides useful advice on how to perform a mature-minor assessment but train-
ees from New Zealand and states and territories in Australia other than Victoria are advised to check local
legislation.

Case Study 2.9
Brooke, 15, attends clinic for review of her cystic fibrosis. During the consultation, she asks for a prescription for the oral contraceptive pill as she plans to become sexually active with her boyfriend. She does not want her parents to know that she is taking the Pill.

(i) Write down the key medico-legal issues relevant to this scenario.

(ii) Outline how you would approach this scenario.

Case Study 2.10
Six months later, Brooke tells you that she stopped taking the Pill when she broke up with her boyfriend. They reunited briefly and she now finds herself pregnant. She wants you to refer her for a termination without telling her parents.

(i) Write down the key medico-legal issues relevant to this scenario.

(ii) Outline how you would approach this scenario.
Case Study 2.11
Anna, 16, has anorexia nervosa. She returns for review and you note that she has had significant weight loss since her last visit. Her pulse rate is 44 bpm. You advise that she needs treatment as an inpatient. She refuses to consent to admission.

(i) Write down the key medico-legal issues relevant to this scenario.

(ii) Outline how you would approach this scenario.

Case Study 2.12
Jonah, 16, has morbid obesity. His body mass index is 41 kg/m2 and he has impaired glucose tolerance and dyslipidaemia. He is desperately unhappy about his weight and has been the victim of bullying at school. He has tried many lifestyle interventions but now wishes to participate in a clinical trial where one of the treatment arms involves bariatric surgery. His parents are opposed to this.

(i) Write down the key medico-legal issues relevant to this scenario.

(ii) Outline how you would approach this scenario.
Clinical Task:

Identify a young person, aged 14-15 years, who is having a medical intervention. Make an assessment of his or her maturity to consent to the intervention.
Further Reading

Journal Articles


Books


Websites

- www.lawstuff.org.au
- www.austlii.edu.au
Topic 3: Therapeutic Engagement

Learning Objectives

To be able to:

° interview an adolescent patient using effective and culturally appropriate communication skills

° conduct a sensitive physical examination of an adolescent patient, being aware of issues relating to body perception and using a chaperone where appropriate

Reading Material


**Interviewing an Adolescent Patient**

Good communication skills are essential for building effective therapeutic relationships with young people. Many of the core principles that apply to interviewing adult patients are equally important for the adolescent age group. Communication may, however, be more challenging with young people than adults because of the need to adapt the consultation to the developmental level of the young person and to balance their emerging independence with their family relationships.

**Opening the Interview**

First impressions can be critical when establishing rapport with a young person during a medical encounter. Greet the young person by name and clearly state your own name and status. Always introduce yourself to the young person first so as to send a clear message that they, not the parent, are the primary focus of the consultation. You may wish to ask the young person to introduce the parent or accompanying adult to you to initiate their participation in the consultation.

**Defining the Boundaries of Confidentiality**

As discussed in the previous section, confidentiality is the cornerstone of any consultation with a young person as it helps to form the basis of a mutually trusting relationship. Make sure that both the young person and their parents understand this concept and are aware of the exceptions to confidentiality from the outset.

**Negotiating for Time Alone**

A corollary to the principle of confidentiality is that the young person needs to be seen alone for part of the consultation. This enables the young person to develop confidence interacting with medical professionals and encourages effective self-management. Seeing the young person alone should usually start about the age of 13 or 14 years, but this will depend on the nature of the presenting problem and the relationship between the young person and their parents. Ideally, the concept of time alone will have been introduced in late childhood. The time allocated to seeing the young person alone can initially be brief but should gradually increase with time.

It is important to communicate clearly to the parents the reasons for seeing the young person alone. Emphasise that consultations with young people on their own should not be seen as undermining the value of parents or the importance of family-centred care. Parents will usually be supportive of your desire to help their child become more independent in the health care setting. During your time alone with the young person, negotiate what can

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1 Sawyer SM and Kennedy A. Care of the adolescent. In, Practical Paediatrics (7th Edition). Editors, Mike South and David Issacs. Churchill Livingston 2012

be discussed with their parents and what is to remain confidential. One strategy is to ask the young person to summarise the content of the interview for their parents when they are back in the room. Not only does this enable the young person to control the flow of information but it provides the clinician with an opportunity to check the young person’s comprehension of what took place during the consultation.

**Clarifying the Nature of the Presenting Problem**

Clarify the reason for the consultation. It may be helpful to establish whether the consultation was initiated by the young person or the parent. If the latter is the case, summarise the parent’s version of the issues and ask the young person to provide their perspective:

“Your mother said she’s worried that you are spending a lot of time alone in your room rather than out with your friends and that you aren’t always remembering to take your medication. She’s concerned that you might be depressed. I was wondering if you could say something about how you see things ...” 3

Be alert to the fact that undifferentiated presentations with non-specific physical symptoms may indicate that the young person is experiencing social or emotional problems.

**Information Gathering**

Encourage the young person to start talking about their presenting problem by asking an open question. Listen carefully to their narrative. Move on to more focused questions if you need to find out additional information. Take into account the young person’s level of cognitive development. Asking complex questions of a young person who is still in the stage of concrete operational thought will usually be unproductive. Even open-ended questions may not work well at this stage of development so questions need to be simple and direct. Avoid using leading questions, such as “You don’t smoke, do you?” or compound questions, such as “Do you not like taking your medication? Do you often miss your tablets?” Always clarify information that you do not understand, especially if the young person uses adolescent jargon.

Provide structure to the interview by using signposting and providing context to your questions:

“... now, we’ve been talking quite a bit about your asthma. If it’s all right, I’d like to ask you about how things are going in other areas of your life right now. I do this as a routine when I see young people, as it can help me understand if anything else might be affecting their health ...”

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3 Adapted from: Adolescent Health. A Resource Kit for GPs. Sydney: Transcultural Mental Health Centre and NSW Centre for the Advancement of Adolescent Health;2004.
This is especially important before broaching sensitive topics, such as sexuality, substance use and mental health problems. The young person will appreciate being asked permission before these topics are explored. A useful technique when asking about sensitive subjects is to normalise the behaviour in question and then circle the topic by asking about the frequency of the behaviour in the young person’s social circle. This can be followed by a question about the young person’s own behaviour.

“A lot of young people your age are starting to date and have relationships. Tell me, is this happening in your friendship group?” …
“What about you?”

Use reflective skills, such as paraphrasing and restatement, to show the young person that you are listening to them. Be responsive to non-verbal cues. Always validate the young person’s input into the consultation and encourage them to ask questions.

**Information Giving**

When providing information to an adolescent patient, use plain language and avoid medical terminology. In late childhood and early adolescence, when there is limited capacity for abstract thought, information will be understood in a literal sense. A young person at this developmental level may not, for example, understand sentences that include idiomatic expressions. Likewise, visual information provided in a conceptual manner also may not convey sufficient meaning to a young person from this age group. For example, using transverse or sagittal sections of the human body to explain the function of the reproductive organs is unlikely to be successful at this developmental level. By mid-adolescence, however, a young person will usually be able to think in more abstract terms about health issues. He or she will be able to grasp concepts such as the difference between variation in physiological functioning [for example, pubertal gynaecomastia in teenage boys] and symptoms due to pathological conditions. By late adolescence, cognitive development will be well advanced and information received in a medical setting will be synthesised in a more comprehensive manner.

**Communication Style**

An interview with an adolescent patient is best approached using an open and friendly manner but do not attempt to be the young person’s friend by using adolescent jargon. Young people are looking for a competent professional to take care of their health needs. Identify and emphasise the young person’s strengths. Be non-judgemental but do not support risky behaviour. Focus your discussion on the behaviour, not the adolescent. Take a neutral stance and try not to side with the young person’s parents.

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4 Lewis J. Physiological and Psychological Development of the Adolescent. Available at: www.yale.edu/ynhti/curriculum/units/1991/5/91.05.07x.html [accessed November 2010]
Cultural and Linguistic Diversity in Adolescent Health Care

Cultural and linguistic diversity adds richness to the fabric of Australia’s multicultural society but it can create challenging situations in the health care setting. Many young people today are growing up between two cultures, which may compound the difficulties of negotiating the transition to adulthood and achieving autonomy from their family. The growing ethnic diversity of the medical workforce furthermore adds to the interplay of cultures in consultations with young people and their families.

Doctors need to be aware of how socio-cultural background can impact on the health beliefs and behaviours of their adolescent patients. It is important, however, to avoid the temptation to stereotype young people. Instead, explore their individual cultural identity. Specifically enquire about cultural issues during the social history and take care to clarify and explore information that is outside your knowledge or experience. Be aware that racism, discrimination and experiences such as war and displacement may be contributing to psychological morbidity in young people who have recently immigrated. Be sensitive to gender issues, especially during the physical examination.

The concept of adolescence can differ between cultures, with some placing greater emphasis on the family than the individual than others. It is important to respect the cultural values of the young person’s family, yet acknowledge the young person’s increasing need for autonomy. Do not use family members as interpreters. Familiarise yourself with multicultural health services that can assist with the care of adolescent patients from non-English speaking backgrounds.


Available from: www.mja.com.au

Dealing with the Reluctant, Resistant or Hostile Young Person

Many young people are struggling to come to terms with their emotions and the physical changes that they are experiencing as they mature into adults. They may also be anxious about being in a health care setting, especially if they have been coerced into attending. This may manifest as difficult or seemingly manipulative behaviour. Adopt a non-judgemental and empathic approach, and validate the young person’s feelings:

“...You seem rather upset about being here today ... I’m guessing that you might be anxious about what’s been happening with your Crohn’s disease at present ... would I be right in saying this?”

If the young person proves difficult to engage, try to depersonalise the focus of the consultation. It may be helpful to provide a hypothetical situation for them to comment on or to offer a menu of responses from which they can select. Another strategy is to make a guess at what they may be thinking or feeling and then ask them to say if you are correct.

Avoid taking an authoritarian approach. Maintain confidentiality unless the young person is deemed to be at risk of harm. If the young person becomes aggressive and hostile, remain calm. Protect yourself and others from harm. Set limits on their behaviour and then try to clarify what they are trying to say to you.


Available from: www.mja.com.au
Clinical Tasks

Practise negotiating time alone with an adolescent patient and his or her parents.

Ask your supervisor or one of your colleagues to observe you gathering information about a presenting problem from an adolescent patient. Ask for feedback about your communication skills.
Conducting a Sensitive Physical Examination

Young people, especially those in early and mid-adolescence, are usually very self-conscious about their bodies and can be shy about removing their clothes for a physical examination. Even a routine examination can be confronting for a young person. These anxieties are often heightened in a young person with a chronic illness. Clinicians need to be sensitive to these issues and conduct the examination in a sensitive, professional and respectful manner.8

Prepare the Young Person for the Examination

Always start the physical examination with a clear explanation of what it will involve and why it is necessary, especially if you plan to perform a general examination. Reassure the young person that a physical examination is a routine component of a medical assessment. Acknowledge the apprehension that adolescents often feel about having a physical examination. It may be helpful to explain what the examination will not involve in order to allay anxiety in the young person. If it is the first time that you have met the young person, ask about their past experiences and whether they have any questions before you start. Avoid using the word “we” as this may be confusing for the adolescent patient.

Offer the young person the chance to have a support person in the room, such as a parent or friend. Be sensitive about cultural and gender issues. If you are a male doctor about to examine a young female patient, it will usually be appropriate to arrange for a chaperone to be present. Allow sufficient time so as not to appear rushed, especially if a sensitive examination is involved. Obtain verbal consent and ensure that the young person is ready to proceed.

Ensure that Privacy and Modesty are Protected

Privacy and modesty are important for young people, just as for adult patients. If indicated, provide a gown for the young person. Make sure that they know what clothes they will need to remove. Do not ask them to uncover more than is required for the examination. You may wish to provide a private area for the young person to change, such as behind a curtain or screen. Ensure that no one can enter the room during the examination and advise the young person that you have done this.

Conducting the Examination

Make sure the examination is conducted in a warm environment. Wash your hands or use an alcohol hand rub prior to commencing the examination. It is preferable that this procedure be completed in front of the young person, as studies have shown that hygiene measures are highly valued by adolescent patients. Ask the young person to remove their gown or top. Do not attempt to remove the young person’s clothing yourself as this can be confronting. If you feel the young person needs help for physical reasons, ask if they would like assistance.

Always start by examining the area of concern as identified by the young person’s presenting problem. If you need to go on to examine another area of the body, state clearly why this is necessary. Talk the young person through the examination. Avoid medical jargon and be aware of the potential for misinterpretation. Be responsive to the young person’s reactions. If the young person seems uneasy, stop and ask if they feel uncomfortable about the examination.

Provide Feedback During Examination

Young people in early and mid-adolescence are often very concerned about whether their bodies are normal. The physical examination provides an excellent opportunity for them to receive reassurance and to learn about how their body changes during adolescence. Provide the young person with specific feedback about their growth and development and be proactive in commenting about normal physiological variations such as unequal breast development in females or the gynaecomastia that occurs relatively frequently in pubertal males. Always finish by asking the young person if they would like to ask any questions about the examination.

Components of the Physical Examination

The physical assessment of an adolescent patient should include measurement of height and weight. These are measured with the young person in bare feet and in light clothes. The results are recorded on a longitudinal growth chart. If growth is falling away from the percentile line, further investigation is warranted. When measuring growth velocity, whole year changes need to be assessed as there can be seasonal variability.

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10 Biro FM. Normal Puberty. UpToDate 2010;18.2.
Measure the blood pressure and compare the result with established norms for age, gender and height.\textsuperscript{11,12} Values between the 90th and 95th percentile are regarded as high-normal, with those above the 95th percentile being classified as high blood pressure. Readings can be affected by anxiety and may need to be taken on more than one occasion. Approximately 1 to 2\% of adolescents will develop consistently high blood pressure, necessitating a search for a secondary cause.\textsuperscript{13}

Examine the cardiac, respiratory and gastrointestinal systems. A neurological examination is usually not required if the adolescent is asymptomatic with respect to this system. Perform a focused musculoskeletal examination to exclude scoliosis or kyphosis of the spine and conditions such as Osgood-Schlatter disease or slipped femoral epiphyses. Look for acne and hirsutism and other abnormalities affecting the skin, such as eczema and tinea.

After these systems have been assessed, the young person is likely to be feeling more comfortable about the physical examination. This is usually the best time to stage pubertal development if this is indicated by the history or if the young person is seeking reassurance about their development. Use a Tanner chart and invite the young person to point to the diagram that best corresponds to their level of development. Do not perform a genital examination unless it is absolutely necessary. A pelvic examination, if required in a young female patient, is best performed by an experienced person, especially if the young person has not had this type of examination before.

Clinical tasks

Practise conducting physical examinations of adolescent patients. Pay particular attention to the process, including briefing the young person beforehand and providing feedback during the examination.

Ask your supervisor or a colleague to observe you while you examine an adolescent patient. Ask them to provide targeted feedback.
Further Reading

Additional Materials


Books

Topic 4: Psycho-Social Assessment

Learning Objectives
To be able to:

- outline the epidemiology of common risk behaviours and mental disorders in adolescence
- discuss risk and protective factors in adolescence
- assess risk and protective factors using the HEADSS screening tool
- identify risk behaviours and common mental disorders in an adolescent patient

Reading Material

Epidemiology of Common Risk Behaviours and Mental Disorders

Experimenting with new behaviours is a normal part of adolescent development. It provides young people with a means of exploring their personal identity and developing functional peer-group relationships. By trying out new behaviours, adolescents can acquire skills that allow them to grow in confidence and to work towards establishing autonomy from their parents. Risk-taking behaviour, however, can lead to harmful consequences. It can interfere with healthy functioning, impact on normal adolescent development and pose threats to health and safety. Psycho-social and contextual factors are key influences on risk-taking behaviour.¹

Young people are often motivated to participate in risky behaviour in order to gain the approval of their contemporaries. This can be fuelled by misconceptions about social norms, as adolescents are prone to over-estimate the incidence of peer group behaviours. Risk-taking behaviour is more likely to lead to adverse outcomes if the adolescent has an impulsive personality or low self-esteem, or does not have the cognitive ability to evaluate the consequences of his or her actions.

Risk-taking behaviour is a major contributor to morbidity and mortality in adolescents in Australia and New Zealand.²,³ More than two-thirds of deaths in this age group are due to accidents caused by behaviours such as driving while under the influence of alcohol. Risk behaviours established in adolescence, such as tobacco and alcohol use, furthermore, set the scene for adverse health outcomes in adulthood.⁴ In general, early onset of risk behaviour results in poorer the long-term health outcomes. Co-occurrence of risk behaviours is common, such that engaging in one risk behaviour is predictive of participation in other hazardous activities.⁵ A clear relationship also exists between abnormal risk behaviour and mental disorders in adolescents.⁶ Risk behaviours, such as alcohol and other drug use, may be used as a way of dealing with unpleasant emotions and can be the first indication of a mental disorder in an adolescent.

⁶ Patton GC. Meeting the challenge of adolescent mental health. MJA 1997;166:399-400.
Risk and Protective Factors in Adolescence

The degree of risk associated with adolescent behaviour depends to a large degree on the balance of risk and protective factors. The presence of risk factors makes it more likely that the young person will engage in behaviours that lead to negative health outcomes. Examples of risk factors in young people include chronic illness, refugee status, family breakdown and bullying, together with parental risk factors such as alcohol abuse, depression and unemployment. Protective factors help prevent the escalation of exploratory risk taking by the adolescent into more harmful behaviour. Examples of protective factors are strong parental guidance, good peer relationships, and participation by the young person in sporting or creative activities that they enjoy and from which they gain new skills. When assessing an adolescent patient, it is important to identify protective factors in addition to risk behaviours. Risk and protective factors fall into four broad domains: the individual, family, peer group and school, and community.7

### Table 4.1: Risk and Protective Factors in Adolescence\(^8,9,10,11,12,13\)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Risk Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>• Low self-esteem</td>
<td>• High self-esteem and efficacy</td>
</tr>
<tr>
<td></td>
<td>• Low intelligence</td>
<td>• Robust intelligence</td>
</tr>
<tr>
<td></td>
<td>• Chronic illness</td>
<td>• Strong moral values</td>
</tr>
<tr>
<td></td>
<td>• Refugee experience</td>
<td>• Creative and sporting pursuits</td>
</tr>
<tr>
<td></td>
<td>• Hyperactivity</td>
<td>• Participation in volunteer work</td>
</tr>
<tr>
<td>Family</td>
<td>• Family breakdown</td>
<td>• Intact family</td>
</tr>
<tr>
<td></td>
<td>• Poor parenting</td>
<td>• Effective parenting</td>
</tr>
<tr>
<td></td>
<td>• Poor relationship with parents</td>
<td>• Positive relationship with at least one parent or other caring adult</td>
</tr>
<tr>
<td></td>
<td>• Parental psychopathology</td>
<td>• Absence of parental psychopathology</td>
</tr>
<tr>
<td></td>
<td>• Family history of risk behaviour</td>
<td>• Family rituals</td>
</tr>
<tr>
<td></td>
<td>• Parental tolerance of risk-taking behaviour</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Low socio-economic status</td>
<td></td>
</tr>
<tr>
<td>Peer Group and School</td>
<td>• Bullying</td>
<td>• Positive peer relationships</td>
</tr>
<tr>
<td></td>
<td>• Peer participation in risk-taking behaviours</td>
<td>• Low peer participation in risk-taking behaviours</td>
</tr>
<tr>
<td></td>
<td>• Poor academic performance</td>
<td>• Scholastic achievement</td>
</tr>
<tr>
<td></td>
<td>• Isolated at school</td>
<td>• Engaged in school activities</td>
</tr>
<tr>
<td></td>
<td>• Low parental interest in education</td>
<td>• High parental interest in education</td>
</tr>
<tr>
<td>Community</td>
<td>• Poor community cohesion</td>
<td>• Stable, connected community</td>
</tr>
<tr>
<td></td>
<td>• Low employment rates</td>
<td>• High employment rates</td>
</tr>
<tr>
<td></td>
<td>• Racial discrimination</td>
<td>• Culture of co-operation</td>
</tr>
<tr>
<td></td>
<td>• Easy availability of drugs and alcohol</td>
<td>• Opportunities for contribution to community</td>
</tr>
</tbody>
</table>

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10 Blum R, Rinehart PM. Reducing the risk: Connections that make a difference in the lives of youth. Youth Studies Australia 1997;16:3–50.


Assessment of Risk and Protective Factors

The early identification of behavioural disorders, emotional issues and mental disorders in an adolescent allows for interventions that can make a positive impact on health outcomes.\(^\text{14,15}\) It is rare, however, that a young person presents with abnormal risk-taking behaviour. It thus falls upon the health care provider to actively screen for and identify these behaviours in adolescents who make contact with the health system. This also includes identifying risk and protective factors in order to make an assessment of overall risk. Evidence, however, suggests that many adolescents presenting for health care do not have adequate psycho-social screening.\(^\text{16}\) As a physician trainee, you can play an important role in ensuring that the risk status of an adolescent patient is adequately assessed.

The HEADSS Screening Tool

The most commonly used tool for exploring risk and protective factors in adolescents is the HEADSS framework. First described in the US in the 1980s,\(^\text{17}\) it is now widely applied as a means of performing a comprehensive psycho-social assessment. The HEADSS framework consists of a set of questions designed to explore the various psycho-social domains that can impact on the well-being of an adolescent. It is a mnemonic for Home, Education/employment, Activities, Drugs and alcohol, Sexuality, Suicide and depression, although since its original description it has been expanded to include Eating/Exercise and Safety (HEEADSSS).\(^\text{18}\) The process of undertaking a psycho-social assessment provides a basis for building rapport with the adolescent patient. It can serve as a mechanism for dealing with minor issues by providing the opportunity for health promotion and anticipatory counselling. It can also serve as a trigger for action and referral in the case of more serious problems.

Using the HEADSS Screen

The HEADSS screen is often introduced after details of the young person’s presenting problem have been elicited, but it can be helpful to use questions from the less sensitive domains as a means of building rapport at the beginning of the interview. You may, for example, choose to comment on a piece of clothing that identifies the young person as being a fan of a certain football team or as being from a particular school, as a means of finding out about their interests or education. It is also often helpful to use signposting when you are broaching psycho-social screening later in the interview, in order to explain its purpose and normalise the process.

“Young people’s health can sometimes be affected by certain behaviours that I’m going to ask you about now. This is something that I do routinely with all young people …”

It is not obligatory to work through the HEADSS screen in any particular order. Rather, it can be tailored to the context, with more emphasis being placed on the domains that appear more relevant to the young person’s presenting problem. It is probably best to start with questions about education rather than home as these are often less threatening, given the complexity of many contemporary families. It is not necessary to cover all aspects in one interview, as it can sometimes take time to work through the whole set of questions. A full screen, however, needs to be completed within the first or second consultation with new patients and be reviewed regularly at subsequent consultations. The table on the following page contains examples of the types of questions to consider within each domain.

It is best to administer the HEADSS screening tool with the young person’s parents out of the consulting room or cubicle, as more accurate information will usually be obtained. It may be helpful to reinforce the notion of confidentiality and its caveats before you start asking about psycho-social matters, particularly more sensitive issues. Use open-ended questions and allow the young person to respond without interruption. You can use more focused questions later on to fill in the gaps. Avoid using leading questions. Also avoid using the HEADSS questions as a check list. Rather, use them as a guide for exploring psycho-social issues. Use sign-posting when approaching the more sensitive areas of questioning:

“Now I’d like to ask a few personal questions. You don’t have to answer these if you don’t want to … the reason that I want to ask these questions is…”


20 Adapted from: Adolescent Health. A Resource Kit for GPs. Sydney: Transcultural Mental Health Centre and NSW Centre for the Advancement of Adolescent Health; 2004
# Table 4.2: The Expanded HEEADSSSSS Framework for Psycho-Social Health Assessment

## Home
- Where do you live?
- Who do you live with?
- How do you get along with each member?
- Who could you go to if you needed help with a problem?
- Have there been any recent changes at home?

## Education and Employment
- What do you like about school/work?
- What are you good/not good at?
- Have your grades changed recently?
- How do you get along with teachers/your employer and other students/colleagues?
- Is there an adult you can talk to at school/work about how you feel?
- Many young people experience bullying at school/work. Have you ever had this happen to your friends? ... And you?
- What are your future plans?

## Eating
- Do you have meals with your family? How often do you do so?
- Who cooks at home? What do you eat?
- Is anyone worried about your weight?
- Are you happy with your weight?
- Do you worry about your weight?

## Exercise
- How do you get to school/work?
- Do you play a sport?
- How often do you do any form of physical activity?

## Activities and Peers
- What do you and your friends like to do for fun?
- Who do you hang out with?
- Do you and your friends go to parties?
- Do you belong to any clubs, groups etc?
- How much TV do you watch each night?
- Do you read for fun?
- How many hours do you use the internet each day?

## Drugs and Alcohol
- Are you on any regular medication?
- Does anybody in your family smoke cigarette or cannabis/drink alcohol frequently?
- Many young people at your age are starting to experiment with cigarettes or alcohol. Have any of your friends done this?
- How about you? Do you drink alcohol or smoke cigarettes?
- How much are you taking and how often, and has your use increased recently?
- What about other drugs like marijuana, IV drugs, amphetamines and ecstasy?
- What effects do drug-taking, smoking or drinking alcohol have on your friends/you?

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### Table 4.2: (continued)

#### Sexuality
- Some young people your age are starting to date and have relationships. Is this happening with any of your friends? What about you?
- Tell me something about the people you have gone out with.
- Some young people your age are getting involved in sexual relationships. Have you been involved sexually with anyone?
- Has anyone touched you in a way that has made you feel uncomfortable or forced you into a sexual relationship?
- What does the term “safe sex” mean to you?
- How do you feel about your own sexuality?

#### Suicide
- How do you feel within yourself at the moment?
- Do you feel sad or more down than usual?
- What sort of things do you do if you are feeling sad/angry/hurt?
- Is there anyone you can talk to?
- Do you feel this way often?
- Some people who feel really down can feel like hurting themselves or even killing themselves.
- Have you ever felt this way?
- Have you ever tried to hurt yourself?
- What prevented you from doing so?
- Do you feel the same now?
- Do you have a plan?

#### Safety
- Have you ever done something you’ve later regretted when you have been drunk or high?
- Have you ever ridden in a car with a driver who was drunk or high?
- Have you ever driven a car when you were drunk or high?
- Have you ever been injured in an accident?
- Have you ever felt that you needed to carry a knife or other weapon to protect yourself?
- Is there any violence in your home?

#### Spirituality
- How would you describe yourself as a person?
- What are you best at?
- How would your best friend describe you?
- Does your family attend a place of worship?
- What do you think about that?
- Do you believe in something outside yourself?
- Who do you talk to when you feel upset about something/when you feel really happy about something?
Talking about sensitive topics may also be facilitated by using a “third person approach” or by “circling” the issue. This involves talking about risk-taking behaviours in adolescents in general before focusing specifically on the young person.

“Some young people your age drink alcohol. What’s happening in your friendship group?” … followed by … “Do you drink alcohol?”

If the young person is having difficulty providing a reply to a question about a sensitive issue, offer a menu of responses from which they can choose.

“You say that you are not really enjoying school at the moment. I am interested in why this might be. Some people don’t enjoy school because they find certain subjects hard, like Maths and English. Others struggle because of difficult students, for example, who might be bullying them …”

Do not assume that questions relating to drug and alcohol use or sexual behaviour do not apply to young people with chronic illness.

Encourage input and questions from the young person during the interview. Provide them with feedback about their psycho-social situation. Acknowledge the aspects of their life that are going well and positively reinforce constructive behaviours. Comment on the areas of the young person’s life that are not going so well.


Using the HEADSS Screen for Health Promotion

The HEADSS framework provides an opportunity for health promotion using anticipatory counselling. This is achieved by providing information about the consequences of certain behaviours as well as providing the adolescent with strategies for dealing with challenges that might arise. This must be done in a non-judgemental manner. Provide feedback and positive reinforcement about constructive health choices.
**Risk Behaviours and Common Mental Disorders**

As well as allowing for the identification of risk and protective factors, the HEADSS screening tool can help to uncover risk behaviours in young people. If you identify risk behaviour in an adolescent patient, explore the issue in order to assess the degree of risk. In the case of substance misuse, establish whether there are any features of dependence. Ask the young person to tell you what they see as the benefits of engaging in the behaviour. Ask them to identify the potential harms of the behaviour, and whether they have any strategies, if any, for minimising harm and preventing escalation. Provide information about the health risks of the risk-taking behaviour in non-judgemental terms and explore the young person's motivation to change their behaviour. Ask them what they perceive to be the drawbacks as well as advantages of behaviour change. If you have serious concerns about a young person’s risk-taking behaviour, discuss these with your consultant.

**Table 4.3: Risk Status Classification**

<table>
<thead>
<tr>
<th>Level of Risk</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Risk</td>
<td>Not engaging in risky behaviour</td>
</tr>
<tr>
<td>Low Risk</td>
<td>Safe experimentation</td>
</tr>
<tr>
<td>Moderate Risk</td>
<td>Some risk to life, health and safety</td>
</tr>
<tr>
<td>High Risk</td>
<td>Major risk to life, health and safety</td>
</tr>
</tbody>
</table>

The HEADSS screening tool also presents an opportunity to detect emotional issues and mental disorders in young people. It is particularly important to screen for anxiety and depression as these are prevalent in the adolescent age group, with chronic illness being a special risk factor. Young people may exhibit depression in atypical ways, such as boredom, with vegetative symptoms such as sleep and appetite disturbance occurring less often than they do in adults. If you identify that a young person has features of depression, it is important to carry out a more in-depth assessment. Ask the young person directly about self harm and suicidal ideation. There is no evidence that asking young people about suicide encourages them in this respect. If the young person is at risk of suicide, urgent referral to a mental health professional is indicated.

Clinical Tasks

Practise performing psycho-social assessments using the HEADSS tool with adolescent patients on the wards or in clinic.

Ask your supervisor or a colleague to observe you carrying out a psycho-social assessment of an adolescent patient for one domain of the HEADSS screen. Ask them to use the checklist in Appendix A to provide you with feedback about your performance.
Further Reading

Journal Articles


Position Statement

Topic 5: Promoting Self Management

Learning Objectives

To be able to:

- discuss the impact of chronic illness on adolescent development
- discuss the impact of physical, emotional and social factors on chronic illness in adolescence
- negotiate a management plan with an adolescent patient and his or her family
- promote self-management skills in an adolescent patient with chronic illness

Reading Material


**The Impact of Chronic Illness on Adolescent Development**

An estimated 15-20% of adolescents suffer from chronic illness or disability.¹ ² Many of these young people need to deal with significant limitations on their daily activities because of their illnesses and require considerable ongoing health care.³ Chronic illness, furthermore, can have a major impact on physical, cognitive and psycho-social adolescent development.

**Physical Impact**

Chronic illness in adolescence can lead to a wide range of physical effects. Delayed puberty and short stature can occur, often caused by nutritional factors. Some conditions, such as spina bifida and cerebral palsy, are associated with precocious puberty. Limitations in physical activity may lead to obesity. Body image issues are often magnified by physical changes associated with medical conditions, leading to significant problems with self-esteem.

**Cognitive Impact**

The impact of chronic illness on cognitive development can be profound. Certain chronic conditions, such as cerebral palsy and spina bifida, can be associated with impaired cognitive functioning. Frequent and extended admissions to hospital can lead to educational disadvantage and impact on socioeconomic status in adulthood. Reduced expectations of the young person with chronic illness by parents and schools can further impact on educational opportunities.⁴

**Psycho-Social Impact**

While some adolescents become more resilient as a result of having chronic illness, many others experience significant emotional distress. Reduced opportunity for socialisation with peers can lead to delayed psycho-social development in young people with chronic illness. Over-protective parents may inhibit the development of independence.

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Impact of Physical and Psycho-Social Factors on Chronic Illness

Physical changes occurring during adolescence can affect the course of a range of chronic illnesses. The hormonal changes associated with the pubertal growth spurt, for example, can impact on glycaemic control in type 1 diabetes mellitus and may increase seizure frequency in epilepsy. The onset of puberty is also linked with an increase in a variety of pain syndromes and a shift to a female preponderance in a number of autoimmune conditions, such as thyroid disease and systemic lupus erythematosis. An association has been observed between early puberty and the severity of asthma in adulthood, as well as the incidence of steroid-dependent malignancies in later life.

Emotional and social factors can also impact on chronic illness in adolescence. Young people with chronic illness experience the same desire to experiment with risk-taking behaviours as do other teenagers, perhaps even more so. In addition, they have greater attributable risk from these behaviours than their healthy peers. Late night parties, for example, can impact negatively on young people with type 1 diabetes mellitus and epilepsy, and smoking has been associated with having a deleterious effect on asthma. The desire for conformity may make young people reluctant to take medication in front of their peers, leading to poor adherence to their treatment regimens. Doctors may exacerbate health risks by assuming the young people with chronic illnesses are not engaging in risky behaviours and thus not provide health promotion information as they would routinely do with other adolescents.

Negotiating a Management Plan

The ideal management plan, according to Gask and Usherwood, is one that reflects current best evidence, fits the patient’s situation and preferences, and addresses not only physical but emotional and social issues. A collaborative approach is crucial, with the patient being an active partner in the decision-making process. These core principles apply with adolescent patients although there is often greater complexity because of the need on the doctor’s part to establish the developmental level of the young person and the degree of involvement of the parents.

Discuss the Treatment Options

When negotiating a management plan with a young person and their parents, start by summarising for the young person the clinical information that you have obtained from the medical interview, the physical examination and laboratory investigations. Indicate that together you need to work out a plan of action. Outline for the young person the investigation and treatment options. Ensure that he or she understands what each option involves. Discuss the benefits and potential side effects of the interventions that you are recommending. If one has greater benefit than another, explain the reason for this. Your role is to guide the young person and their parents, but not to make the decision for them. Be sure to also clearly explain the consequences of delaying or not pursuing further investigation and treatment. The young person may need time to come to their decision. This needs to be respected and may involve making another appointment at a later time.

Develop the Management Plan

When the treatment option has been determined, map out a plan of action with the young person, taking into account their particular circumstances. Try to keep the management plan as simple as possible. In the case of a pharmacological intervention, find out from the young person which regimen will best suit their daily routines. Explain to the young person using plain language how the treatment is to be used, taking into account their cognitive level. Ask if they think the management plan is realistic and if they foresee any difficulty adhering to it. Specifically asking the young person to identify which parts of the plan will be easy to adhere to and which will be difficult can be an effective way of gauging the appropriateness of the plan.

Check that the Young Person Understands the Management Plan

The young person may be reluctant to say that they do not fully understand your instructions. Ask them if there is anything they don’t understand about the management plan. Check their understanding by asking them to repeat the plan back to you. Also ask the young person’s parents about their understanding of the plan.

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Provide developmentally appropriate printed material or write down the details of the management plan. Ask if they have any questions or would like to discuss any other issues relating to their health care.

**Ensure that Appropriate Support is in Place**

Assess what level of support is required for the young person to implement the management plan. Most young people will be reliant on their parents in at least some aspects of their management. The degree to which the adolescent’s parents are engaged will depend on the developmental level of the young person and the type of problem being treated. Clarify how much monitoring the young person’s parents currently provide. Recognise that parents will typically have anxieties about the ability of their child to self-manage their medical condition both now and in the future, and will usually be grateful for support. Ask the young person how their parents might best support them in adhering to specific aspects of the management plan.

**Arrange Appropriate Follow-Up**

Discuss how the management plan will be reviewed. Arrange a follow-up appointment for the young person and assist with any referrals that may be necessary. Review within a short time-frame is usually required with an adolescent patient, at least initially. Ensure that they know how to contact you or their general practitioner if they have any questions or concerns.
Clinical Tasks

Practise negotiating a management plan with an adolescent patient.

Ask your supervisor or a colleague to observe while you negotiate a management plan with an adolescent patient. Ask for feedback about your performance, using the checklist in Appendix B.
Promoting Self Management Skills

The management of chronic disease can be complex and, in contrast with that of acute illness, highly dependent on patient self-management. The responsibility for the management of chronic conditions in children predominantly lies with parents. As young people with chronic illness mature, they learn to take increasing responsibility for day-to-day management of their condition. The development of self-management skills is an important component of the transition to adult health care.

To be able to manage a chronic illness, an adolescent requires a sound knowledge of their particular condition. He or she needs to be able to monitor the symptoms and signs of the condition, to adhere to a treatment regimen that has been negotiated with health care providers and to adopt a lifestyle that helps to prevent complications of the condition. Being able to access and use support services is also a critical component of self-management. Doctors play a critical role in helping young people with chronic illness meet these goals.


Chronic Condition Self-Management Skills

The skills, behaviours and attitudes required to manage a chronic illness are not necessarily instinctive and most people, especially adolescents, require assistance from their health-care practitioners to become effective in self-management.10 Chronic Condition Self Management Support (CCSMS) is a term that is sometimes used to describe the skills that health professionals need in order to help patients manage their chronic illnesses.11 One core skill of CCSMS is promoting adherence to a management plan.

Promoting Adherence to a Management Plan

A trusting relationship is important in helping a young person adhere to a treatment regimen. An atmosphere where honesty and confidentiality are valued is likely to promote free exchange of information. Young people are also more likely to be engaged in the therapeutic process if they understand the rationale for their treatment and they have been an active partner in developing their management plan.

11 www.som.flinders.edu.au/FUSA/CCTU/workshops.htm
It is important to check the young person’s level of adherence to the management plan during every consultation.\textsuperscript{12} Do not assume that the young person is adhering to the plan. Very few people, including adults, do this all the time. Use language that reflects this:

\begin{quote}
“Many young people I see find it difficult to remember to take their medications routinely. How have you been doing with your puffers?”
\end{quote}

Be aware that levels of adherence can differ between various components of the young person’s management plan. Enquire about each therapeutic intervention separately. Identify barriers to adherence and recognise that issues with adherence may simply be due to the fact that the young person has other priorities in his or her life at the present time. Other common factors that can impact on adherence are financial problems, depression, difficulty accepting the illness and side-effects of medication. The treatment may interfere with the young person’s lifestyle, generating reluctance to adhere to the regimen. This is especially likely if the treatment is perceived as being embarrassing, such as self-administration of insulin by injection in type 1 diabetes mellitus.

Adherence may be suboptimal because the young person does not fully understand the treatment regimen but is reluctant to admit this. It is usually helpful for the doctor to discuss self-management in terms of the young person’s confidence rather than their knowledge:

\begin{quote}
“I know that you have been working with the dietitian on your carbohydrate counting. How confident do you feel about using it to adjust your doses of insulin?”
\end{quote}

Emphasise the positive benefits of adhering to the management plan rather than the potential detrimental affects of not doing so:

\begin{quote}
“… and if your asthma is well controlled, you will be able to do all the things that you like to do … like staying over with your friends and doing sport …”
\end{quote}

The focus needs to be placed on helping with practical strategies rather than on problems. Tailor the medication regimen to suit the young person’s daily routine and encourage them to use a reminder system. Support the young person in developing their own strategies to promote adherence. Short-term goals are more likely to motivate young people, especially in early and mid-adolescence when the cognitive ability to visualise the future is limited. Use written action plans and repeat instructions frequently. Offer information to the young person about peer support programs.

\textsuperscript{12} Osterberg L, Blaschke T. Adherence to medication. NEJM 2005; 353:487–97.
Engage their parents in ways that the young person finds helpful. Parents are generally still very important in helping the young person adhere to their management plan. Ensure that they know how their role will change with time.

Provide anticipatory guidance by identifying situations where it might be difficult to adhere to the treatment regimen. Encourage the young person to develop strategies to cope with such situations:

“Now when you go on holidays, it might not be as easy to remember to take your medication as when you are at home. What do you think you could do to make sure you remember?”

Give effective feedback to the young person about how they are managing their illness. It is often helpful to start by asking the young person to identify the components of the treatment they think they are managing well and those that need more work. This usually results in the feedback process being more interactive. Provide specific information about the young person’s progress and give positive reinforcement about effective management strategies.

Involve the parents and acknowledge any concerns that they may have about how the young person is managing their illness. They are more likely to provide a realistic assessment of the degree of adherence but take care not to side with the parents against the young person. Many adolescents feel that their parents repeatedly ‘nag’ them about taking their medications. Discuss with the young person how they can show their parents that they can be trusted while encouraging the parents to respect the young person’s growing autonomy. Make sure, however, that parents do not hand over responsibility to the young person prematurely.
Clinical Tasks

Practise talking with adolescent patients about adherence. Specifically ask about their adherence to various elements of their treatment plan, such as medication, monitoring, physiotherapy and special dietary requirements. Ask about the aspects of their treatment that they do not like.

Ask your supervisor or a colleague to observe you talking with an adolescent patient about adherence. Ask them to use the checklist in Appendix B - Negotiating a Management Plan with an Adolescent Patient to provide you with feedback about your performance.
Further Reading

Journal Articles


Books


Websites

**Topic 6: Transition to Adult Care**

**Learning Objectives**
To be able to:
- describe the principles of transition from paediatric to adult health care
- effectively facilitate transfer from paediatric to adult health care

**Reading Material**

Principles of Transition from Paediatric to Adult Health Care

More than 90% of children with chronic illness now survive into adulthood.\(^1\) An important part of the management of these young people is the effective transition of their care from paediatric to adult health care services. Transition to adult health care is more than just a change of geographical location; rather, it embodies a broader concept whereby, according to Blum et al, there is a “purposeful, planned movement of young people with chronic physical and medical conditions from child-centred to adult-orientated health care systems.”\(^2\)

For most young people, transition to adult care is an exciting time. They appreciate the recognition that they have outgrown the paediatric setting and are now adults. They also value the opportunity to receive more sophisticated and age-appropriate medical advice, such as that relating to sexual health and other lifestyle issues. In addition, successful transition can send an important message to young people with chronic illness that they are valued and can make a meaningful contribution to society as young adults.

Although the importance of effective transition is now widely acknowledged, it often occurs in less than ideal circumstances. Young people may be transferred to adult health care before they have sufficiently well-developed skills to function independently. This can contribute to their being lost to follow up, often with significant adverse health consequences.\(^3,4\) Conversely, young people may stay longer in the paediatric system than is developmentally appropriate.

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Various attitudinal and structural barriers to effective transition have been identified. Some young people may be reluctant to leave a familiar paediatric health care setting due to fear of the unknown. Parents may also be unwilling for their child to progress to adult health care, for fear of losing input into decision making. Parents and doctors may have concerns about the quality of care the young person will receive in the adult health care setting. In some instances, these concerns are valid, especially where disease-specific expertise or appropriate multi-disciplinary services are lacking, or where care is limited by funding constraints that did not apply in the paediatric setting. The adult environment, furthermore, may seem unfriendly or threatening to young people, particularly if their care is delivered in proximity to older patients in poor states of health.

Most of these barriers can be overcome with a structured and co-ordinated approach to transition, the principles of which have been articulated in various position statements by professional bodies, including the Royal Australasian College of Physicians. Ideally, the process of transition starts when the young person is in early adolescence. Strategies such as seeing young people on their own for increasing periods of time during consultations and promoting autonomy with respect to self-management lay the foundations for successful transfer to adult health care.

Physical transfer of care should occur when the young person’s health status and social circumstances are stable. In Australia, transfer usually takes place when secondary school education has been completed, whereas in New Zealand it often takes place earlier. A decision about the precise timing of transfer to adult health care, however, should be based on individual need, and in consultation with the young person and their family. The developmental level of the young person must be taken into consideration, including the degree to which they are achieving independence from their family. It is not necessary for a young person to have acquired all of the skills necessary for self-management prior to transfer, as some of these they may only be gained by being in an adult health care setting.

Handover of information to adult services and continuity of care for the young person need to be arranged with close co-operation between paediatric and adult services. The young person’s general practitioner needs to be actively involved in the process, as appropriate and responsive primary care is a vital component of transition. It is specifically important to ensure that the young person has a close relationship with their general practitioner, as they may have previously relied on their specialist paediatrician for many of their basic health care needs.

Some paediatric hospitals now have transition co-ordinators to oversee transfer to adult care.10 Likewise, many adult health care facilities have developed strategies for receiving young people that acknowledge their specific health care needs. Some adult hospitals, for example, run young adult clinics designed to cater for young people in the 18-25 year old age group who have specific chronic illnesses, such as type 1 diabetes mellitus. These clinics often have adult and paediatric doctors in attendance together to promote continuity of care. Successful transition ends with the full integration of the young person into the adult health care system.

Facilitating Transfer from Paediatric to Adult Health Care

The process of facilitating transfer from paediatric to adult health care primarily involves ensuring that the young person has developed their chronic illness self-management skills to a sufficient degree that they can function in an adult health care environment. Ideally, the young person will have a sound knowledge of their medical condition and its complications, as well as its treatments and potential side effects. They also will need to know how to contact their health care provider if any problems arise. The young person should have their own Medicare card, be proficient in managing appointments independently and be able to fill prescriptions in a timely manner. A physician receiving an adolescent into the adult health care system has the responsibility to ensure that the young person consolidates and further develops their chronic illness self-management skills.

Facilitating effective transfer also involves close collaboration between the young person, their family and the general practitioner, as well as any other health care providers who will be involved in on-going care. If the young person does not have their own general practitioner, help them to find someone suitable. Depending on the nature of their chronic illness, some young people will be transferred to a multi-disciplinary adult health care team in a hospital setting, while others will be referred for community or private specialist care. Not all young people who have required specialist paediatric care will require transfer to adult specialist care. Regardless of the type of adult health care required, careful planning is needed to ensure that transfer occurs in a timely and streamlined manner. Documentation between health care practitioners needs to be accurate and comprehensive, and should indicate the specific areas, if any, in which the young person needs further help in developing their self-management skills. Confidentiality issues need to be respected so it is important to provide the young person with an opportunity to view and amend the transfer summary. It is also important to supply them with a copy of the final version of the summary.

If a young person is being referred to an adult hospital, it may be helpful to arrange a visit for them and their family prior to transfer so they can familiarise themselves with their new health care environment. Ideally, there will be a contact person in the adult setting who is responsible for receiving the young person and co-ordinating their medical care. Health care outcomes for the young person after transfer can be optimised by having professionals in the adult setting who have a sound understanding of adolescent development. Planning should also include strategies for seeking help in an emergency, should this occur during the transfer period.

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11 Note that there is no equivalent to Medicare in New Zealand

Clinical Task

Interview a patient aged between 17 and 19 who has a chronic illness. Complete the Transition Self-Management check list from Appendix C and assess their readiness for transition. If they have already made the transition to adult health care, ask about their experience of the process.

Clinical Task

If possible, attend a Young Adults clinic and observe how it operates.
Further Reading

Journal Articles

• Rosen DS. Transition to adult healthcare for adolescents and young adults with cancer. Cancer 1993;71:3411-3414.


• Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. Arch Dis Child 2008;93:160-163.

Websites


• www.rch.org.au/transition/prof.cfm

• www.iaah.org
Additional Materials and Resources

Books


Book Chapters

Chapters on adolescent medicine are included in the following textbooks of paediatrics and internal medicine:


Websites


European Youth Forum. Available at: www.youthforum.org

The Society for Adolescent Health and Medicine (SAHM). Available at: www.adolescenthealth.org


American Academy Pediatrics. Available at: www.aap.org

NZ Society for Youth Health Aotearoa Professionals Available at: syphanz.tripod.com

Adolescent Health Journals

The Journal of Adolescent Health, published by the US Society for Adolescent Medicine, reports new research findings in the field of adolescent medicine, ranging from basic biological and behavioural sciences through to public health and policy. Other specific adolescent health journals include Adolescent Medicine Clinics, Adolescent and Family Health and the International Journal of Adolescent Medicine and Health.

Scholarly research in adolescent medicine also appears in periodicals for internal medicine, paediatrics, psychiatry, endocrinology, sports medicine, infectious diseases, obstetrics/gynaecology and other interdisciplinary journals such as Journal of Youth and Adolescents, Journal of Adolescence, Developmental Psychology, Adolescence, Journal of Early Adolescents, Journal of Research on Adolescence and Journal of Adolescent Research.

Adolescent Health Conference

The Australian and New Zealand Adolescent Health Conference is convened annually by various groupings of adolescent physicians and related health professionals in Australia and New Zealand.
Centres for Adolescent Health in Australia and New Zealand:

Centre for Adolescent Health
Royal Children's Hospital
50 Flemington Road
Parkville VIC 3052
Australia

Tel: 613 9345 5890
Fax: 613 9345 6343
www.rch.org.au/cah

NSW Centre for the Advancement of Adolescent Health
Level 1 Main Building
The Children's Hospital at Westmead
Cnr Hawkesbury Road & Hainsworth Street
Westmead NSW 2145
Australia

Tel: 612-9845 3338
Fax: 612-9845 0663
www.caah@chw.edu.au

Kidz First Centre for Youth Health
95 Wiri Station Road
Manukau
Manukau City
New Zealand

Tel: (09) 261 2272
Fax: (09) 261 2273
Email: cfyh@middlemore.co.nz
www.healthpoint.co.nz/default,23135.sm
## Adolescent Psychosocial Health Assessment

### Interview Appraisal Tool

**Patient Gender:**
- [ ] Male
- [ ] Female

**Patient Age:** ___

**Date:** ______

<table>
<thead>
<tr>
<th>Leave item blank if not applicable</th>
<th>Done Well</th>
<th>Satisfactory</th>
<th>Poor</th>
</tr>
</thead>
</table>

### Introduces the Concept of Psychosocial Screening

- Uses sign-posting to introduce psychosocial screening
- Explains purpose of psychosocial screening
- Normalises the process of psychosocial screening

### Uses Effective Generic Communication Skills

- Demonstrates active listening skills
- Uses a balance of open and focussed questions
- Clarifies information effectively
- Does not use jargon or technical language

### Uses Adolescent-Focussed Communication Skills

- Takes into account developmental level
- Begins with non-sensitive subject matter
- Reviews confidentiality if broaching sensitive issues
- Uses a “third person” approach for sensitive issues
- Offers menus of options to facilitate discussion
- Encourages input and questions from the young person

### Provides Feedback and Health Promotion

- Acknowledges aspects that are going well
- Positively reinforces constructive behaviours
- Acknowledges aspects that are not going well
- Addresses risky behaviour without being judgemental
- Provides anticipatory guidance

### Feedback on Overall Performance

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### Assessor

Signature:
# Negotiating a Management Plan with an Adolescent Patient

## Interview Appraisal Tool

**Patient Gender:** 
- Male
- Female

**Patient Age:** ____

**Date:** ________

<table>
<thead>
<tr>
<th>Leave item blank if not applicable</th>
<th>Done Well</th>
<th>Satisfactory</th>
<th>Poor</th>
</tr>
</thead>
</table>

### Introduces Management Phase of Consultation
- Summarises findings from clinical assessment
- Checks young person’s understanding of health status
- Outlines process of developing a management plan
- Discusses importance of collaborative approach
- Takes into account developmental level
- Involves the parents appropriately in the consultation

### Develops Management Plan with Young Person
- Discusses management options
- Outlines risks and benefits of each option
- Establishes young person’s preferences and priorities
- Discusses consequences of not pursuing management
- Demonstrates effective information giving skills

### Plans Implementation with Young Person
- Maps out management plan with young person
- Elicits optimal regimen for young person
- Elicits young person’s confidence to implement plan
- Asks young person to identify potential difficulties

### Checks Understanding and Ensures Support
- Checks young person’s understanding of plan
- Offers developmentally appropriate written information
- Assesses level of support required from parents
- Asks if young person has any questions or comments
- Arranges appropriate follow-up

### Feedback on Overall Performance

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**Assessor:**

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**Signature:**
## Transition Self-Management Check List

**Patient Gender:**  
- [ ] Male  
- [ ] Female  
**Patient Age:** ____  
**Date:** ________

<table>
<thead>
<tr>
<th>Leave item blank if not applicable</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

### Has Sound Knowledge of Medical Condition
- Can name and explain medical condition  
- Can describe current health status  
- Can list medications and other treatments  
- Can explain why each treatment is required  
- Can discuss potential side-effects of each treatment

### Can Self-Manage Medical Condition
- Can prioritise health care over other desires  
- Can remember to take medication most of the time  
- Can ask questions of health care professionals (HCPs)  
- Responds appropriately to questions asked by HCP  
- Can consult with HCP without parents in attendance

### Can Negotiate Health Care System Effectively
- Has own Medicare card  
- Can fill a prescription in a timely manner  
- Can manage appointment scheduling  
- Knows how to contact HCP in an emergency  
- Knows how to contact appropriate advocacy group

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**General Comments**