Adolescents with Chronic Conditions

Around 10-20% adolescents have a chronic illness:

- The majority of chronic illness originates during childhood
- Approximately 80% of children with chronic illness survive into adulthood
- Serious conditions or injuries, particularly those related to accidents, can also be acquired during adolescence

Chronic Illness and Adolescence

Young people with a chronic illness face additional difficulties on top of the normal developmental challenges of adolescence:

- Chronic illness can prolong adolescence for physical and/or psychosocial reasons:
  - pubertal development may be slowed down
  - parental overprotection limiting autonomy
  - limitation of peer contacts due to hospitalisations
  - lack of opportunity for employment
- Dependency on parents and other people at a time when independence is an important developmental goal for them
- Isolation because of dislocation from school and peers
- Being perceived as *'abnormal'* at a time when *'normality'* and peer acceptance are crucial concerns for adolescents

The Adolescent with a Chronic Illness ***see page 128***

- Chronic conditions can become exacerbated or unstable as a result of behaviours and adherence issues associated with adolescent development
- The course of an illness can change during adolescence
  - *epilepsy* may commence or worsen
  - *asthma* may worsen with the impact of stress, non-compliance or smoking
  - *diabetes mellitus* frequently becomes more brittle and difficult to control
- Be prepared to address sexuality and relationships concerns – even adolescents with disabling chronic illness have the same sexual aspirations as their peers
- Do not assume that all adolescents with a chronic illness will be affected in the same way

Management Approaches *see page 128*

- Focus on the individual young person and their capacity for healthy functioning rather than the disease per se
- Use a developmentally appropriate approach – taking into account the age and developmental stage of the young person
- Provide the young person and parents with strategies for enhancing adherence
- Encourage autonomy, self-reliance and responsibility for self-management of the illness
- Help them focus on what they can do – in terms of their interests, activities, lifestyle – rather than on what they *can't* do
- Limit intrusive medical examinations or procedures
- Provide honest and easily understood information about the condition and its consequences – do not focus solely on negative consequences
- Educate and support parents – help them to reduce over-anxiety, over-attention and over-protectiveness
- Use the relevant **Medicare Item Numbers** to promote a collaborative treatment approach for asthma, diabetes and other chronic conditions

Transition Care *see page 130*

- GPs can play a key role in assisting an adolescent patient in their transfer to adult health services by:
  - taking an active role in case management or shared care with specialist teams
  - collaborating with other professionals and services in the process of the young person's transition
  - addressing their holistic health care needs

Managing Obesity *see page 131*

- Obesity is a chronic disorder of energy imbalance – **focus on promoting changes to both sides of the energy equation – energy in and energy out**
- Measure the adolescent's body mass index (BMI) and plot on a BMI-for-age chart
- **Lifestyle change** is the basis of weight management:
  - dietary modification
  - reduction in sedentary behaviours
  - an increase in physical activity and behaviour modification
- Adopt a **developmentally appropriate approach:**
  - for younger adolescents – work with the parents and adolescent together
  - for older adolescents – work with them individually as well as with parents

chapter eleven
Adolescents with Chronic Conditions

Around 10-20% of adolescents have one or more chronic illnesses such as asthma, diabetes or cystic fibrosis[1]:

- the majority of chronic illness originates during childhood
- medical and surgical advances are continually improving survival
- approximately 80% of children with chronic illness survive into adulthood – increasing the importance of a smooth transition to adult care
- serious conditions or injuries, particularly those related to accidents, can also be acquired during adolescence

Key Principles

- As with all adolescent patients, establish a trusting relationship and recognise the young person's developmental needs
- Relate to the *young person* first and foremost as a young person – that is, treat them as an *'adolescent with diabetes (or asthma, etc.)'*, rather than a *'diabetic adolescent'*
- In managing chronic conditions in adolescents, it is essential to understand the developmental context of the illness – that is:
  - the impact of the illness on the young person's development, and
  - the impact of 'normal' adolescent developmental issues on the illness and its management
- Young people with chronic conditions experience the same health and social issues as their healthier peers – therefore it is important to address a range of concerns such as growth and development, mental health, sexuality, nutrition, exercise and health risk behaviours such as drug and alcohol use[2]
- You can use the ***HEEADSSS*** psychosocial assessment to identify concerns in different areas of the adolescent's life and to detect the presence of risk and protective factors

See Chapter 2 – Conducting a Psychosocial Assessment

- Pay particular attention to maintaining the young person's confidentiality and gaining informed consent as they traverse different systems and engage with different health professionals[3]

Chronic Illness and Adolescence

Young people with a chronic illness may experience additional difficulties on top of the normal developmental challenges of adolescence[1, 4]. It is important to consider the impact of the condition on the young person's development[5]:

- Chronic illness can impede the fulfilment of the normal bio-psychosocial developmental tasks of adolescence – e.g.
  - **Biological** – impact on growth and puberty
  - **Psychological** – impact on identity formation, body image, cognitive development
  - **Social** – impact upon development of autonomy, family relationships, peer relationships, sexuality, educational and vocational achievements
- Chronic illness can prolong adolescence for physical and/or psychosocial reasons:
  - pubertal development may be slowed down, particularly related to undernutrition
  - parental overprotection limiting autonomy
  - limitation of peer contacts due to hospitalisations
  - lack of opportunity for employment – particularly if there is a physical disability or shortened life expectancy
  - lack of appropriate role models
- Dependency on parents and other people at a time when independence is an important developmental goal for them
- Isolation because of dislocation from school and peers
- Being perceived as *'abnormal'* at a time when *'normality'* and peer acceptance are crucial concerns for adolescents

Impact of Chronic Illness at Different Stages of Adolescence

- The impact of chronic illness, and the challenges they face, can differ according to the young person's stage of development – e.g.
  - **Early** – there may be pubertal delay, distortion of body image and isolation from peers
  - **Middle** – enforced dependency and less acceptance by peers are especially difficult to handle
  - **Late** – reduced vocational options; concerns about relationships and possibility of having children predominate

The Adolescent With A Chronic Illness[1]

In managing a young person with a chronic illness, it is also important to recognise that adolescent developmental issues can impact on the progress of the chronic condition, and the young person's adherence to management regimes[5]:

- Chronic conditions can become exacerbated or unstable as a result of behaviours and adherence issues arising out of otherwise normal adolescent developmental processes – e.g. the struggle for identity, autonomy and the effects of peer relationships and sexual development can compromise adherence to management plans
- Adolescents who have lived with chronic illness since childhood may experience less negative impact of their illness as they go through adolescence
- The course of an illness can change during adolescence
  - *epilepsy* may commence or worsen
  - *asthma* may worsen with the impact of stress, non-adherence or smoking
  - *diabetes mellitus* frequently becomes more brittle and difficult to control.
- Be prepared to address sexuality and concerns about relationships – adolescents even with disabling chronic illness have the same sexual aspirations and fantasies as their peers
- While it is important to understand the impact of chronic illness on adolescence, do not assume that all adolescents with a chronic illness will be affected in the same way

Coping with Chronic Illness[4]

- ***Psychological responses to illness*** – may be viewed as important ways to diffuse or diminish anxiety:
  - responses such as denial, intellectualisation, compensation and regression are generally adaptive in helping the young person to cope with their illness
  - extreme hostility, panic, withdrawal or suicidal behaviour are clearly maladaptive and require more active psychological intervention
- ***Promote positive coping behaviours*** – encourage participation in 'normal' activities:
  - maintain a network of friends (with and without disability)
  - participate in sports and social activities where possible
  - involvement with household chores or part time employment if appropriate
  - promote self-perception as not handicapped

Issues Related to the Condition[1]

- *Age of the young person* – the early adolescent going through puberty appears to be most vulnerable
- *Visibility of the condition* – a more visible disability is often associated with less stress and psychological distress
- *The degree of functional impairment* – impaired mobility can be demoralising and socially handicapping, with mild gait disturbances causing more emotional difficulties than more severe limitation
- *Prognosis* – the stress of uncertainty is greater than when the course is known, even when the clinical trajectory leads to death
- *Course of the illness* – a stable or predictable course is less distressing than a fluctuating and unpredictable one

Management Approaches[1, 4]

- Focus on the individual young person and their capacity for healthy functioning rather than the disease per se
- Acknowledge that the chronically ill adolescent has the same developmental needs as other young people
- Use a developmentally appropriate approach – taking into account the age and developmental stage of the young person

- The young person generally places greater emphasis on other aspects of their life (i.e. normal adolescent priorities and concerns) above their illness
- Parents and doctors however, tend to put more emphasis on the young person's symptoms and illness:
  - this has important implications for adherence to treatment regimes which may conflict with their need to participate in social and peer activities
- Provide the young person and parents with strategies for enhancing compliance

See also Chapter 12 – Enhancing Compliance

- Encourage autonomy, self-reliance and responsibility for self-management of the illness
- Help them focus on what they *can* do – in terms of their interests, activities, lifestyle – rather than on what they *can't* do
- Limit intrusive medical examinations or procedures
- Provide honest and easily understood information about the condition and its consequences – do not focus solely on negative consequences
- Educate and support parents – help them to reduce over-anxiety, over-attention and over-protectiveness
- A multidisciplinary approach to treatment is essential in the management of many chronic illnesses – specific **Medicare Item Numbers** exist for asthma, diabetes and other chronic conditions that can be used to facilitate a collaborative treatment approach
- Consider referral to a psychologist or social worker for supportive counselling – to address psychosocial and family issues

See Chapter 13 – Collaborative Care – for relevant Medicare item numbers

Management of Specific Conditions

It is beyond the scope of this Kit to provide in-depth guidelines for management of specific chronic conditions. However, a number of excellent resources exist which provide treatment guidelines for different conditions.

Asthma

- Asthma is the second most common chronic illness of the teenage years (16 per cent of 12 to 15 year olds are diagnosed with asthma) [6]
- Adolescents with asthma are a vulnerable group at high risk of experiencing complications of their illness [6]
- Because of competing lifestyle and developmental priorities, young people have a tendency to ignore their symptoms and may have trouble taking medication regularly

resources

There are a number of website and services offering information and support for asthma sufferers, as well as tools and guidelines for GPs:

- **National Asthma Council** provides links to the top asthma management resource tools from the National Asthma Council Australia for GPs and Health Professionals www.nationalasthma.org.au
- **Asthma Australia** has a website for the association of all the Asthma Foundations throughout Australia, containing resources for parents and adolescents on management of asthma – www.asthmaaustralia.org.au
- ***When Your Child Has Asthma*** Van Asperen, P., Davis, A., Towns, S. (2007). Simon & Schuster. Sydney. This book can be very helpful for GPs as well as parents and adolescents with accessible explanations of current asthma evidence and practice incorporating the latest NAC guidelines, devices and management

Diabetes

- A number of typical adolescent lifestyle and risk behaviours can potentially compromise effective control and management of diabetes – e.g. eating habits; alcohol use
- Specialist consultation and collaboration with a multidisciplinary team is essential in management of diabetes, especially Diabetes Mellitus Type 2 [7]

resources

The following websites provide resources for diabetes sufferers and their families, as well as resources and guidelines for GPs and health professionals:

- Diabetes Australia
  www.diabetesaustralia.com.au
- Australian Diabetes Educators Association
  www.adea.com.au
- Australasian Paediatric Endocrine Group
  www.ape.g.org
- CME on Diabetes Australia
  www.cmeondiabetes.com.au

Transition Care

The transition from child or adolescent-focused health services to more independently oriented adult services can be challenging for young people and their families, as well as for the health professionals that support them.[8]

Transition is defined by the Society for Adolescent Medicine as "the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems".[8]

The ultimate aim of transition is to promote the young person's capacity for self-management of their chronic condition – particularly during the early teenage years (12-16 yrs – preparation phase) and to facilitate a smooth transition to adult care (16-18 yrs – active transition phase) thereby improving long term health outcomes.[8]

During the active phase, it has been shown that visiting adult services, joint clinics between adult and paediatric services and having their first appointment arranged are very helpful in assisting the young person's transition.[9]

- GPs can play a key role in assisting an adolescent patient in their transfer to adult health services by:
  - taking an active role in case management or shared care with specialist teams
  - collaborating with other professionals and services in the process of the young person's transition
  - addressing their holistic health care needs
- It is important to include the young person and their family as active participants in the transition process
- Confidentiality should be maintained for the adolescent as they traverse systems and engage with different health professionals[8]

GMCT Transition Care Network

- The Greater Metropolitan Clinical Taskforce Transition Network (GMCT) commenced in 2004 – the program extends across all Area Health Services in NSW
- It aims at improving the continuity of care for young people with chronic health problems as they move from paediatric to adult health services
- The GMCT can assist GPs by:
  - helping to find appropriate adult health services
  - helping to prepare young people and their family for the move to adult health services
  - providing information and support when they transfer from children's services and follow up to help make sure they stay engaged in adult services
- There are three Transition Care Coordinators based in the three paediatric health care networks at Westmead, Royal Prince Alfred, and John Hunter Hospitals who can be contacted for support with transition care:
  - **The Western Area – (02) 9845 7787**
  - **South Eastern Area – (02) 9515 6382**
  - **Hunter New England Area – (02) 4925 7866**

The Children's Hospital at Westmead has a Transition Co-ordinator and Transition to Adult Care Committee that facilitates transition for adolescents attending the hospital and works closely with the adult hospital-based Transition co-ordinators – **(02) 9845 2446**.

resources

- NSW Health's **Transition Care Website** provides a range of support and resource materials for young people and their families
- It also provides resources and guidelines for health professionals
  www.health.nsw.gov.au/gmct/transition
- **CHIPS** Chronic Illness peer support program for young people – www.rch.org.au/chips
- **The Children's Hospital at Westmead Website** has information for parents and adolescents www.chw.edu.au go to 'Parents/fact sheets/chronic illness/transition'

Case Study - Chronic Illness

Mary is a 15 year old girl and in Year 10 at school. She lives with her parents and two older brothers. She has had insulin dependent diabetes since age 8 and has attended your surgery and hospital outpatients regularly, for reviews, with her mother accompanying her. Her diabetes control had been quite stable until a year ago. Two months ago she had an admission to hospital for ketoacidosis.

Mary attends with her mother one afternoon after school. Both seem upset and angry. Her mother says that Mary has been 'eating all sorts of rubbish' and that she cannot understand why she is unable to see the dangers of this and how it could land her back in hospital. Mary argues with her mother in front of you that she only had some Coke and a few lollies when some school friends came over on the weekend.

You suggest to both of them that having diabetes and being a teenager can be very difficult and that Mary might be feeling stressed. Mary looks more defiant at this point and her mother looks even more upset. You suggest that it might be good for you to have a talk to Mary on her own and her mother very reluctantly leaves the room.

Management Approaches

- It is important to get to know Mary on her own, and in the context of her family, peers and culture, to assess her health risks, health concerns, and strengths. Beginning to separate Mary from her mother during consultations will facilitate this, and should be done sensitively. Her mother remains an important member of the 'management team'
- Some of the following may be operating and it will take time to formulate a further management plan. For example:
  - Mary may be experiencing significant adjustment difficulties because she is in mid-adolescence and feels 'different' from her peers
  - Mary's mother might be overprotective, because she has diabetes and this is causing tensions in their relationship
  - Mary might be stressed because she has missed school and a significant part of her Year 10 assessment, due to her illness and hospital admission
- Using the ***HEEADSSS*** assessment will help to explore the above (and other) psychosocial issues – e.g. sexuality, relationships, peer groups, etc.

Managing Obesity

Obesity can be considered both as a disease, with its own significant morbidity and mortality, and as a risk factor for other non-communicable diseases, including type 2 diabetes and cardiovascular disease.[9]

- Up to 30% of males and 22% females12-24 years old are overweight or obese[10] – making overweight one of the most common chronic disorders of adolescence[11]
- Physical activity is declining in young people – in 2004-2005 only 46% on males and 30% females aged 15-24 participated in recommended levels of physical activity
- Adolescence is one of the critical life periods for the development of obesity
- Obese adolescents have a greater than 80% risk of becoming obese adults[9]
- There are many physical, psychosocial and developmental complications of overweight and obesity in adolescence

Raising the Issue of Weight Problems

Young people are generally very sensitive about their body image. They may be reluctant or embarrassed to discuss the issue of their weight. Therefore, it is important to engage the young person in a trusting relationship which will allow you to sensitively raise the issue of their weight.

Strategies for engaging the young person about their weight:[11]

- Use feeling well and being fit as engagement language
- Make the conversation relevant to what is concerning the patient (e.g. improving the chances of playing in team sport, clearing the skin, feeling more in control and less tired)
- Make time to obtain an adequate assessment of their personal situation – young people are generally very happy to talk about themselves and valuable management insights will be gained – you can use the ***HEEADSSS Assessment*** to assist with this

- Avoid the desire to use the argument about future health issues – parents are likely to be worried about these but not the young person
- With both young people and their parents:
  - avoid stigmatizing or blaming
  - stay solution-focused and supportive

Assessment [9, 11]

- A full weight history will need to be taken over several consultations
- Explore lifestyle – including eating habits, exercise patterns and leisure time/recreation (e.g. hours spent watching television; computer use; etc.)
- Obtain a more in-depth history of their dietary habits and food intake – this can include the young person keeping a food and activity diary
- Explore in detail the factors influencing physical activity, sedentary behavior and dietary intake
- Obtain family history – particularly any history of overweight, type 2 diabetes, dyslipidaemia, early heart disease and hypertension
- Screen for the presence of depression or other mood disorders and psychosocial problems
- A physical examination should be performed – height and weight should be measured and body mass index (BMI) calculated and plotted on a BMI-for-age chart
- Overweight is considered >85th BMI percentile and obesity >95th BMI percentile
- Laboratory investigations may be necessary to identify metabolic risk factors, or to exclude secondary causes of overweight or obesity
- It is also important to consider cultural background, as some ethnic groups may be at greater risk of diabetes

Management [9, 11]

- Obesity is a chronic disorder of energy imbalance – **focus on promoting changes to both sides of the energy equation – energy in and energy out**
- Adopt a **developmentally appropriate approach:**
  - for younger adolescents – work with the parents and adolescent together
  - for older adolescents – work with them individually (as well as with parents) –to tailor interventions around their priorities, motivation for change and developmental concerns (such as peer acceptance, self-image, need for independence)
- Actively involve the parents (and other family members) as agents of change in terms of both dietary and exercise habits, as well as supporting the young person in their behaviour change program
- **Lifestyle change** is the basis of weight management – the **NHMRC guidelines** suggest using a combination of the standard behavioural interventions[12]:
  - dietary modification
  - reduction in sedentary behaviours
  - an increase in physical activity and behaviour modification
- **Set realistic behaviour change and weight loss goals** – help the young person to feel comfortable with their body image and self-esteem, while at the same time promoting behaviour and lifestyle change
- Address underlying or contributing psychological and psychosocial issues, such as depression and anxiety – where necessary, refer to a Psychologist or Social Worker to address these issues
- Plan for a long term intervention – as the required behaviour change will take time
- More intensive therapies for more severe degrees of overweight may require specialist consultation

Behavioural Management of Obesity[9]

Be specific in setting behaviour change goals – for example:

1. ***Long term dietary change***
   - reduce energy intake
   - choose lower fat foods
   - reduce intake of high sugar foods and drinks
   - avoid severe dietary restriction
2. ***Increase in physical activity***
   - increase incidental activity
   - choose active transport options (e.g. walking, cycling)
   - participate in more physical lifestyle activities (e.g. sports)
   - participate in more organised activities
3. ***Decrease in sedentary behaviour***
   - decreased use of television, computer and other electronic entertainment
   - use alternatives to motorised transport

resources

- **Much of the material presented above is drawn from the following articles, which provide in-depth approaches to assessment and management of obesity:**

  Baur, L. and Burrell, S. (2005). Managing Obesity in Childhood and Adolescence. *Medicine Today* 6(7):46-56.

  Steinbeck, K. (2007). Adolescent overweight and obesity: How best to manage in the general practice setting. *Australian Family Physician* 36(8):606-612.
- See also **NHMRC Clinical practice guidelines for the management of overweight and obesity in children and adolescents**
  www.health.gov.au/internet/wcms/publishing.nsf/content/obesityguidelines-guidelines-children.htm
- **BMI calculators and curves** are available from the Royal Children's Hospital, Melbourne
  www.rch.org.au/genmed/clinical.cfm?doc_id=2603

practice points

- In managing chronic conditions in young people, it is essential to consider the impact of the illness on the young person's physical and psychosocial development
- It is also important to recognise that adolescent developmental issues can effect the chronic condition, and the young person's adherence to management plans – e.g. the struggle for identity, autonomy and the effects of peer relationships and sexual development can compromise adherence to management plans
- Focus on the individual young person and their capacity for healthy functioning rather than the disease per se
- Encourage autonomy, self-reliance and responsibility for self-management of the illness
- Use the relevant **Medicare Item Numbers** to promote a collaborative treatment approach for asthma, diabetes and other chronic conditions
- GPs play a key role in assisting an adolescent patient in their transition to adult health services by:
  - taking an active role in case management or shared care with specialist teams
  - collaborating with other professionals and services in the process of the young person's transition
  - addressing their holistic health care needs
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  - reduction in sedentary behaviours
  - an increase in physical activity and behaviour modification
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  - for younger adolescents – work with the parents and adolescent together
  - for older adolescents – work with them individually as well as with parents

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3 Sanci, L., Sawyer, S.M., Kang, M., Haller, D., Patton, G. (2005). Confidential health care for adolescents: reconciling clinical evidence with family values. *Medical Journal of Australia* 183(8):410-414.

4 Sanci, L. (2001) *Adolescent Health Care Principles*. Centre for Adolescent Health. The Royal Australian College of General Practitioners. Melbourne.

5 Berg-Kelly, K. *Presentation from European Training in Effective Adolescent Care and Health (EuTeach)* – <www.euteach.com> viewed 10 December 2007.

6 Van Asperen, P., Davis, A., Towns, S. (2007). *When Your Child Has Asthma*. Simon & Schuster. Sydney.

7 Strasburger, V., Brown, R., Braverman, P., Rogers, P., Holland-Hall,C., and Coupey, S. (2006). *Adolescent Medicine: A Handbook for Primary Care*. Lippincott, Williams & Wilkins. Philadelphia.

8 Royal Australian College of Physicians. *Transition to Adult Health Services for Adolescents with Chronic Conditions*. RACP Health Policy and Advocacy, Paediatric and Child Health <www.racp.edu.au> viewed 16 April 2008.

9 Craig, S.L., Towns, S., Bibby, H.(2007). Moving on from Paediatric to Adult Health Care: An Initial Evaluation of a Transition Program for Young People with Cystic Fibrosis: *International Journal Adolescent Med Health* 19(3):333-343.

10 Baur, L. and Burrell, S. (2005). Managing Obesity in Childhood and Adolescence. *Medicine Today* 6(7): 46-56.

11 Australian Institute of Health and Welfare (2007), *Young Australians, their Health and Wellbeing*, Cat No. PHE 87. AIHW, Canberra <www.aihw.gov.au> viewed 10 December 2007.

12 Steinbeck, K.(2007). Adolescent overweight and obesity: How Best to Manage in the General Practice Setting. *Australian Family Physician* 36(8):606-612

13 National Health and Medical Research Council (2003). *Clinical practice guidelines for the management of overweight and obesity in children and adolescents*. <www.health.gov.au/internet/wcms/publishing.nsf/content/obesityguidelines-guidelines-children.htm> viewed 16 April 2008.