

SECTION 3.11

CHRONIC CONDITIONS AND DISABILITY

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MELISSA KANG

Ten to 20 per cent of adolescents have one or more chronic conditions. Most chronic conditions develop in childhood. Chronic conditions include, but are not limited to, asthma, diabetes and cystic fibrosis (Bennett and Kang 2001). Serious conditions or injuries, particularly those related to accidents, can also be acquired during adolescence.

The term “disability” includes impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure. An activity limitation is a difficulty encountered by an individual in executing a task or action. A participation restriction is a problem experienced by an individual in involvement in life situations (World Health Organisation (WHO) 2012).

Disabilities may be classified into five main groups as described by the Australian Institute of Health and Welfare:

1. Intellectual
2. Psychiatric
3. Sensory/speech
4. Acquired brain injury
5. Physical/diverse

In young people aged 15-24, physical conditions were the main reported health condition causing disability (62 per cent of those with a disability) followed by mental or behavioural disorders (39 per cent) (AIHW 2010, p. 19).

Whereas once the diagnosis of a chronic condition or a disability might have reduced the life expectancy of a child significantly, medical and surgical advances are continually improving survival rates (Bloomquist et al. 1998).

Most young people with chronic conditions and disabilities experience the same health and social issues as their healthier peers. In responding to their healthcare needs, 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 (Rosen et al. 2003).

As with all young people, establishing a trusting relationship based on respect for the young person

as an increasingly independent individual is the foundation of good health care. Remember that the young person is a person first: they are an adolescent with asthma or epilepsy or a disability, not an asthmatic, epileptic or disabled adolescent.

For the best possible health outcomes, it is important to understand the developmental context of the condition or disability:

- What is the impact of the condition or disability on the young person’s development?
- What is the likely impact of ‘normal’ developmental issues on the condition or disability and its management?

You can use the HEEADSSS psychosocial assessment (see 3.2 Psychosocial assessment) to identify concerns in different areas of the young person’s life and to detect the presence of risk and protective factors.

Young people with a chronic condition or disability may experience additional difficulties on top of the normal developmental challenges of adolescence (Bennett and Kang 2001; Sanci 2001). It is important to consider the impact of the condition on the young person’s development (Berg-Kelly 2007).

Chronic conditions and disabilities interact with the normal bio-psychosocial developmental tasks of adolescence. Biologically, an illness or disability can affect growth and puberty. Psychologically, it can affect identity formation, body image and cognitive development. Socially, it can have a lasting impact on the development of autonomy; family, peer and sexual relationships; the formation of sexual identity; and on educational and vocational achievements.

Adolescence can be prolonged for young people with a chronic condition or disability:

- Pubertal development may be slowed down, which is particularly related to under-nutrition.
- Parental overprotection because of the chronic condition or disability may limit autonomy.
- Peer contact and connection as well as schooling can be disrupted by hospitalisations or limited mobility.
- Young people experience reduced opportunities for employment – particularly if there is a physical disability or shortened life expectancy.
- Young people with chronic conditions or a disability often lack appropriate role models.
- A young person with a chronic condition or a disability may be highly dependent on parents and other people at a time when independence is an important psychological developmental goal.

- A young person with a chronic condition or disability may be perceived as 'different' at a time when 'normality' and peer acceptance are crucially important to young people.

You can maximise positive health outcomes for a young person with a chronic condition by promoting positive coping behaviours and encouraging participation in normal activities. Support the young person to:

- Maintain a wide network of friends
- Participate in sports and social activities where possible
- Participate in household chores or part time employment if appropriate
- See themselves as capable (Sanci 2001).

A number of factors can influence the experience of adolescence for a young person with a chronic condition or a disability. These include:

- Age at diagnosis– diagnosis in the early adolescent years when going through the rapid physical and emotional changes of puberty can be difficult.
- The degree of functional impairment – impaired mobility can be socially disabling and is not necessarily related to the severity of the disability (for example, mild gait disturbances may result in more emotional difficulties as the young person struggles to fit in).
- Prognosis – conditions associated with uncertain outcome are challenging with the stress of uncertainty affecting the young person's psychological wellbeing and hindering their ability to create a vision for their future.
- The course of the condition – a stable or predictable course is less distressing than a fluctuating and unpredictable one.
- Level of knowledge and self-efficacy – those who understand their condition are more likely to avoid high risk behaviours and have better health (Bennett and Kang 2001).

CO-MORBIDITIES

An estimated 7per cent of all young people in Australia reported some form of disability. Of this percentage just over one-quarter (27 per cent) identified as having a severe disability (AIHW 2011). Health gaps between adolescents that have a disability and those who do not remain large. In young people (15-24yrs) physical conditions were the main reported health condition causing disability (62per cent of those with a disability) followed by mental or behavioural disorders (39per cent) (AIHW 2010, p. 19).

Those with severe or profound disability had higher prevalence rates of long-term health conditions than people without a disability. They are more likely to:

- Have slightly higher rates of obesity, and more likely to do a very low level of exercise or no exercise
- Start smoking before 18 years
- Have mental health problems (48 per cent compared to 6 per cent)
- Have considered committing suicide
- Have been diagnosed with diabetes or a high sugar level (23 per cent had diabetes or a high sugar level before the age of 25 years versus 7 per cent)
- Have acquired arthritis before the age of 25 (14 per cent versus 6 per cent) (AIHW 2010)

A young person may be diagnosed with a primary disability such as autism but can experience co-morbidities (one other disabling condition) or multiple disabilities (more than one other disabling condition) at the same time. Multiple disabilities in childhood were mostly associated with intellectual disability, which affects around two to three per cent of the population. Almost 60 per cent of people with intellectual disability have severe communication limitations and are also likely to have limitations in other activities such as self-care, mobility and communication (AIHW 2008).

The most common co-morbidity with intellectual disability is mental illness.

More than half of people aged 15–44 years with acquired brain injury or intellectual disability had three or more disabilities. Support needs of people with early onset multiple disabilities vary depending on the nature of their disabilities and their life stages. As they grow older, they are likely to require more support at an earlier age than people with single or late onset disability (AIHW 2009).

DISABILITY AND MENTAL HEALTH

People with a disability exhibit the same range of mental health disorders and problems as general population, however young people with disabilities are more likely than those without a disability to experience mental health problems or disorders early. Fourteen per cent of young people with severe or profound disability and mental health problems experienced the onset in childhood or adolescence compared to 7per cent of those without disability (AIHW 2010).

Young people with a disability have many of the known risk factors for developing mental health issues. These may include:

- Pre-natal brain damage, birth injury or complications
- Physical and intellectual disability
- Poor health
- Low intelligence
- Chronic conditions
- Poor social skills
- Low self-esteem
- Alienation

Identifying mental health problems and disorders in children and adolescents with an intellectual disability is complex. It requires a collaborative approach involving a variety of health professionals.

Early intervention is important to reduce the impact of mental illness in later life. Interventions may include prevention or strategies to reduce the impact of child abuse and neglect; behavioural interventions to reduce maladaptive behaviours or enhance social competence; and educational assistance to enhance academic ability and social skill (AIHW 2009).

If you suspect that a young person you are working with is experiencing psychological stress or mental health issues problem is suspected, a referral from a GP to a paediatrician, psychologist or psychiatrist is needed. Alternatively, child and adolescent mental health services in the public system can arrange access to paediatric psychologists and psychiatrists, and can refer on to a specialist psychologist or psychiatrist working in intellectual disability. If the young person is over 18 they will be referred to adult services.

IMPROVING THE HEALTH CARE EXPERIENCE

All young people moving through adolescence have a growing need for independence and autonomy. This applies to young people with a chronic condition or a disability too. Support the young person to develop the skills and confidence they need to manage both their condition or disability and the developmental tasks of adolescence. This includes taking an active role in their own health care and making decisions about treatment and management options. Giving young people the freedom to choose is an important empowerment strategy in assisting them to take more control of their health.

Consider developing a chronic condition/disability care plan in consultation with the young person

and their family/carer. It should include emergency management plans and will need to be updated regularly. The young person can share this with their family and with school staff.

Develop and communicate a clear understanding of the roles, responsibilities and expectations of each person in the management team, including the young person. Consider whether a referral to a psychologist or social worker for supportive counselling might be useful to help the young person negotiate any particularly stressful aspects of managing their health and wellbeing.

Parents and doctors tend to focus on the management or treatment of a young person's symptoms and condition. However, it is also important to consider the impact of the condition or disability and any treatment necessary on education, social interaction, workforce participation and other relationships. It is particularly important to consider the implications of treatment plans for an adolescent's need to participate in social and peer activities.

Provide the young person and parents with strategies for enhancing adherence, such as establishing structured routines, regularly reviewing treatment plans and building flexibility into therapy wherever that is possible.

Above all, encourage autonomy, self-reliance, responsibility and confidence for self-management of the condition or disability. Help the young person focus on what they can do – in terms of their interests, activities, and lifestyle – rather than on what they can't do

TRANSITION CARE

When a young person with a chronic condition moves from paediatric health services to adult health services this process is called transition. The transition from child or youth-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 (Steinbeck et al. 2007, 2008; Wood et al. 2011).

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) and to facilitate a smooth transition to adult care (16-18 years) to improve long-term health outcomes.

Visiting adult services, attending joint clinics between adult and paediatric services, and having their first appointment with new providers arranged can be helpful in assisting the young person's transition (Craig et al. 2007).

Health professionals can play a key role in assisting patient young person 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
- Empowering the young person to make decisions and attend appointments on their own
- 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 young person as they traverse systems and engage with different health professionals.

All health professionals are encouraged to refer young people to transition services from 14 years so that these services can prepare young people well in advance for the move over to adult services. There is evidence that an early referral for transition results in better health outcomes for the young person – although it's never too late to refer.

NSW TRANSITION SERVICES

In NSW, there are comprehensive transition services for young people with chronic conditions or disabilities and their families/carers. The goal of transition services is to support young people to live a full and rewarding life while successfully managing their own health, to the best of their ability. It is important that young people feel well prepared to make the leap into adult health services. This can take time and planning. The earlier this preparation starts the better chance a young person has of making a smooth, easy and sustainable transition, resulting in long term health and social benefits. Some young people may not be able to manage their own health care once they turn 18 and parents, relatives and carers will continue to do this for them. Transition services also assist families and carers through the transition process.

Maintaining the engagement of young people during transition will improve their health outcomes and reduce the time they may spend in hospital. Raising transition with the young person's clinical team early in adolescence will encourage early planning which is necessary for an effective transition. Moving to a new adult setting in the community or a hospital can be daunting, and this may result in the young person dropping out or losing control of managing their health care. This may then impact on their health and wellbeing negatively. It is therefore extremely important for young people to

be supported through the transition process and to start planning at the age of 14.

There are two transition services in NSW working in collaboration to ensure young people with chronic conditions and disabilities are supported during their transition. Young people with chronic conditions and their families/carers known to The Sydney Children's Hospitals Network (SCHN) can be referred to Trapeze. Those who are not known to SCHN can be referred to the Agency for Clinical Innovation (ACI) Transition Care Network. The age criterion for both services is 14-25.

Transition services can assist by:

- Finding appropriate adult health care services and attending those appointments if requested;
- Preparing young people for the move to the adult health services;
- Find a GP who is sensitive the needs of young people;
- Making sure the young person's GP has updated information to provide the best possible care;
- Working close with the GP to implement a GP Management Plan and Team Care Arrangements;
- Providing information about obtaining a Medicare card, Health Care Card, and financial assistance;
- Communicating with the clinical teams and providing advocacy;
- Sending SMS appointment reminders;
- Talking through accommodation, education, and work options;
- Offering confidential telephone and face to face support;
- Assisting with obtaining medication and equipment;
- Providing information about health care rights and responsibilities;
- Linking with support groups;
- Teaching skills on how to manage their condition so young people are in control; and
- Offering support for parents/carers/guardians; and
- Providing regular contact with the young person to make sure they have successfully engaged with the adult health service.

TRAPEZE: A SUPPORTED LEAP INTO ADULT HEALTH

Trapeze is the specialist transition service for The Sydney Children's Hospitals Network (The Children's Hospital at Westmead and Sydney Children's Hospital, Randwick). Trapeze supports young people with chronic conditions and their families/carers aged 14-25 known to SCHN to make the leap from their children's hospital to adult health services.

The aim of Trapeze is for young people to better manage their conditions as they move over to adult services so they can live their own lives and stay out of hospital. Trapeze facilitates, monitors and coordinates a young person's care during transition and strengthens their links with local adult services, especially their GP. The staff at Trapeze work closely with the young person's GP as this relationship is integral for the young person. The GP is ideally placed to provide a safety net during the transition process and to take increasing responsibility as a care coordinator and advocate for the young person.

Trapeze focuses on the whole person providing an integrated and holistic approach to health care ensuring the young person is at the centre of the transition process at all times. Trapeze believes young people have the right to be heard, to make genuinely informed choices and have timely access to medical services.

Trapeze can be contacted by:
Phone: 02 8303 3600
Email: trapeze.schn@health.nsw.gov.au
Website: www.trapeze.org.au

THE AGENCY FOR CLINICAL INNOVATION (ACI) TRANSITION CARE NETWORK

The Agency for Clinical Innovation (ACI) provides three Transition Care Coordinators in NSW who are based in adult hospitals and provide a state-wide service. Their role is to ensure continuity of care for young people aged between 14-25 years of age with any chronic conditions/ disabilities as they move to the adult health service.

The Transition Care Coordinator can assist the young person in providing information about adult health services; sorting out any difficulties in finding or attending adult health services; providing guidance/support at adult clinics; helping to adjust to a new adult team and a new adult service; and providing regular contact with the young person to make sure they have successfully engaged with the adult health service.

The Transition Care Coordinators can be contacted by phone:
The Western Area – (02) 9845 7787
South Eastern Area – (02) 9515 6382
Hunter New England Area – (02) 4925 7866

FINDING OUT MORE...

There are many services offering information, education and support about chronic conditions, disability and adolescence.

- Children with Disability Australia (CDA) is the national peak body representing children and young people (aged 0-25) with disability and their families. Visit www.cda.org.au
- Livewire is an online community for young people living with a serious illness, chronic health condition or disability and their families. Visit www.livewire.org.au
- The special School-Link program hosted by the Children's Hospital at Westmead promotes collaboration between disability, health and education sectors to provide information and resources related to young people with an intellectual disability and mental health. Visit www.schoollink.chw.edu.au
- The NSW Council for Intellectual Disability (NSW CID) represents the rights and interest of people with intellectual disability in NSW. Their website has fact sheets on mental health and disability. Visit www.nswcid.org.au
- Physicalasanything.com is a web-based resource written by experts for teachers, schools, healthcare professionals, students and families. Endorsed by the NSW Department of Education and Communities and NSW Health, the website provides detailed descriptions of more than 50 conditions affecting school-aged children and young people and the educational implications of each condition. Visit www.physicalasanything.com.au.
- The NSW Agency for Clinical Innovation, Trapeze, and The Sydney Children's Hospitals Network have produced Key Principles of Care for Young People Transitioning to Adult Health Services, which is reproduced in the appendix of this Kit.

CHAPTER SUMMARY - WHAT TO REMEMBER

In managing chronic conditions and disability in young people, it is important to consider the impact of the condition on the young person's physical and psychosocial development.

It is also important to recognise that adolescent developmental issues can affect the condition itself and the young person's adherence to management plans. The search for identity, the need for greater autonomy, and the effects of peer relationships and sexual development can compromise adherence to management plans.

Focus on the individual young person and his or her capacity for healthy functioning rather than just on the chronic condition or disability.

REFLECTION QUESTIONS

How well does your service address the needs of young people with disability?

How well do you support young people with chronic conditions who need to transition to adult services?

How can you improve the transition of young people to adult services?

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