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Transition of Young People with a Chronic Health Condition to Adult Health Services

Background

Adolescence is a time of rapid development, physically, cognitively and socially. Young people need preparation and support to become autonomous adults.¹ For young people with a chronic health condition, this process is more complex and difficult. Differences between the paediatric and adult health systems create barriers to accessing optimal levels of health care for young people with a chronic health condition who have reached the age limit to utilise paediatric services.

The Society for Adolescent Medicine defines transition 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...²
Proactive transition to the adult health system encourages young people to be successfully integrated into a comprehensive care system to meet their complex needs.³

The rates of chronic conditions in young adults are increasing,⁴ and more than 90 per cent of children with chronic conditions now survive into adulthood⁵ producing an increased demand for ongoing therapy and care.

Young people with a chronic health condition often require the services of a range of health providers. An effective, organised and coordinated process in which the young person is transferred from the paediatric to the adult health care system is crucial to their continued well-being and willingness to engage with ongoing health support and treatment.⁶ Poorly managed transition can lead to preventable co-morbidities, reduced productivity and life expectancy and additional long-term costs to health services. Despite this, there are currently significant discrepancies across different jurisdictions in the provision of effective multi-agency assessment, planning and implementation of transition. This is, in part, due to a lack of coordination between paediatric and adult services as well as a critical lack of key workers to assist with transition.

The APA position

The APA supports the principles for successful transition of young people with a chronic condition proposed by the UK Department of Health, Child Health and Maternity Services Branch⁷, the Royal Australian College of Physicians⁸ and the Ontario Centre for Childhood Disability Research.⁹

The APA believes that physiotherapy has a vital role in the initiation, facilitation and provision of care for young people with a chronic health condition transitioning to adulthood. This ranges from involvement in working with young people and their families in goal setting and planning long term management, to specific physiotherapy interventions which optimise health and well-being. Physiotherapists are appropriately trained and possess the skills and knowledge to assume a lead role in the transition process.

The APA believes that planned, coordinated transition should be available for all young people with a chronic illness regardless of geographical location, or type of chronic illness. For some individuals, a multidisciplinary team may be required to manage care; however, it is proposed that the continued involvement of a primary health worker, such as the individual's general practitioner, is essential to evaluate and address the young person's needs.

Readiness for transition varies according to many factors including: developmental readiness, complexity of health problems, characteristics of the adolescent and family and the availability of health professionals. Consequently, the determination of readiness for transition should incorporate a flexible set of criteria to address the unique needs and requirements of each individual and their family. Preparation of the young person and their family for the process of transition should commence at least two years before the transfer to adult service care is expected to occur. Prior to commencement of transition, management plans should be developed as part of a collaborative partnership between the young person, their family, paediatric and adult rehabilitation providers (such as physiotherapists) and other key professionals.

Health and disability providers and services, including non-Government providers, need to work in collaboration with each other and their clients to assist with transition. Consistent aims and goals are required to provide a seamless transition for young people with chronic conditions, and to meet their care needs, which are sometimes very complex.

The APA believes that there are currently insufficient resources, particularly in workforce, to optimally support transition. Governments should commit to a substantial financial investment to explore workforce gaps, establish dedicated resources for transition coordinators and expand collaborative multidisciplinary teams located in the appropriate paediatric and adult settings.

There is also a need for an expansion in training and education for health professionals to increase their capacity to deliver developmentally appropriate health services for young people.

Improving access to health services during transition care

The APA believes that improving access to health care resources for young people with chronic conditions is vital to supporting and encouraging them to maintain engagement with the healthcare system and to optimally manage their condition(s).

Access could be improved by establishing a set of best practice guidelines to ensure that the services and care provided allow young people to reach and maintain optimal well-being.

The following issues need to be taken into consideration:

- The possible challenges that a young person undergoing transition may face need to be identified and addressed. Care should be person-centred and demonstrate an appropriate level of flexibility regarding expected compliance with treatment and achievement of adult behaviours.
- The need to explore and promote the effective use of technology to engage young people and encourage them to be responsible with their own care. For example, young people can be supported by the deployment of electronic reminders and notifications of appointment schedules and medication regimes.
- Advantage should be taken of home-based monitoring options and self-management strategies for the condition(s) should be promoted and supported.
- The use of Individual Electronic Health Records to monitor progress and optimise outcomes of transition care should be explored and promoted.
- Personal, environmental and financial barriers that disadvantage young people from accessing health providers and services should be identified and addressed. For example, the provision of public transport fare support and concessions may assist young people to attend appointments when no private modes of transport are available.
- Barriers that prevent young people from accessing appropriate aids and equipment should be identified and addressed. These may include, but are not limited to, funding inequities, lack of expertise in equipment provision and lack of availability of technological support.

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