

# TRANSITION TO ADULT HEALTH SERVICES FOR ADOLESCENTS WITH CHRONIC CONDITIONS

## **Background**

In our current generation, more than 90% of children with chronic illnesses and conditions survive to adulthood.<sup>1</sup> The transition from family-oriented, developmentally focussed paediatric 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.<sup>23</sup>

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". This paper assumes that transition to adult health care is important for all health conditions. The term "transition" refers to a complex set of attitudes, skills and processes that facilitate this movement, while the term "transfer" refers to the change in service delivery from paediatric to adult services. <sup>5</sup>

Coordinated community youth based services, school based services, primary and specialty health care services are all important in the management of adolescents and young people with chronic conditions. There is a lower rate of engagement by this population with traditional primary health care (General Practice) services, and therefore lesser access to important preventive services e.g. immunisation, sexual health promotion, contraception etc.

The paediatric and adult specialist health systems are often quite different, and moving to the adult system may create new barriers to accessing health care for young people. These may include lack of developmentally appropriate support and additional financial costs. Developmentally appropriate health services promote the transition between child and adult oriented services, encourage engagement in an appropriate level of health care (including primary health care) and reduce the risk of young people "dropping out" of health care.

The difficulty in engaging young people and the often high drop out rate once transfer of care occurs <sup>6</sup> underpins the need for active case management and follow-up by the paediatrician until a relationship with the adult physician is established. Discussion with the new case managing adult physician is an integral part of the transition process.

This policy is aimed at all primary, secondary and tertiary health care providers involved in the clinical care of adolescents and young people with chronic health conditions. This population, also known as young people with special health care needs, is estimated to comprise approximately 12% of all young people in Australia and New Zealand. <sup>7 8,9</sup>

### **Aims**

The aim of successful transition of young people to adult health services is to optimise both their health and their ability to adapt to adult roles. The ultimate aim is to promote the young person's capacity for self-management of their chronic condition and to improve their life chances.

While this process is not the same for all young people, a set of principles underpin a successful transition process. These are based on the notions of flexibility, responsiveness, continuity, comprehensiveness, and coordination.<sup>1</sup>

# Principles of Successful Transition to Adult-Oriented Health Services<sup>10</sup>

- 1. Health care services for adolescents and young people need to be developmentally appropriate and inclusive of the young person's family where appropriate.
- 2. Young people with chronic illnesses and conditions share the same health issues as their healthier peers. Health services therefore need to holistically address a range of concerns such as growth and development, mental health, sexuality, nutrition, exercise and health risking behaviours such as drug and alcohol use.
- 3. Health care services require flexibility to be able to deal with young people with a range of ages, conditions and social circumstances. The actual process of transition needs to be tailored to each individual adolescent or young person.
- 4. Transition is generally optimised when there is a specific health care provider who takes responsibility for helping the adolescent or young person and his or her family through the process.
- 5. Active case management and follow up helps optimise a smooth transfer to adult health services as well as promoting retention within adult services.
- 6. Engagement with a general practitioner can address holistic health care needs and help reduce the risk of failure of transfer to adult services.
- 7. Close communication between paediatric and adult services will help bridge cultural and structural difference of the two health systems, resulting in smoother transition of young people to adult services.
- 8. An ultimate goal of transition to adult health care services is to facilitate the development of successful self-management in young people with chronic conditions.

#### Recommendations

- 1. All young people with a chronic illness or disability should have a health care provider who takes specific responsibility for their transition to adult health care. This includes the coordination of community, primary, specialty and allied health services, as well as the development of up-to-date detailed written transition plans, in collaboration with young people and their families.
- 2. There needs to be additional care taken in the transition into adult health care of vulnerable young people without family support, or in the care of the state. These young people are more likely to have a wider range of medical and psychosocial needs, and the transition to adult care may be more difficult.
- 3. The adult service provider should accept responsibility for active case management and follow up once the young person has left the paediatric service.
- 4. The development of a portable, accessible, medical summary will facilitate the smooth collaboration and transfer of care between health care professionals.

- 5. The core competencies required by health care providers to render developmentally appropriate health care and facilitate health care transition should be an integral component of basic and advanced training requirements for all physicians. These same skills are expected of all health care providers involved in the care of young people.
- 6. Affordable, comprehensive, and continuous health care should be accessible to young people with chronic conditions throughout adolescence and into adulthood.. All young people with chronic illness should have a primary care provider.
- 7. The same standards for primary and preventive health care should apply to young people with chronic conditions as to their healthy peers. This includes a focus on wellness that incorporates biological, psychosocial, vocational, and educational needs. This can be achieved by using a developmental approach, and ensuring that a comprehensive psychosocial assessment is performed by the health provider coordinating the care of the young person.
- 8. Confidentiality must be maintained for the adolescent or young person as they traverse systems and engage with different health professionals. Careful consideration to confidentiality and informed consent needs to be paid to young people during these years. <sup>11</sup>
- 9. Fellows of the Royal Australasian College of Physicians can advocate for appropriate clinical services in both paediatric and adult services in order to facilitate the process of transition and to help reduce barriers to successful transfer in the long term.

### **Further Reading**

This is one of a series of policies on adolescent health being produced by the Joint Adolescent Health Committee of the Royal Australasian College of Physicians.

The others include:

- Routine health screening in adolescence
- Confidentiality in Adolescent Health

### References

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