



Transition from paediatric to adult health services: maintaining the health of young adults with chronic conditions.

A Chronic Illness Alliance Position Statement.

May 2009

Many childhood onset paediatric conditions such as cystic fibrosis, haemophilia, epilepsy, type 1 diabetes, thalassaemia, cancers and thyroid conditions have had poor prognoses but with new medications, and recent advances in treatments children are now surviving into adulthood. In order to maintain their health and quality of life, young people with chronic conditions require smooth transition from paediatric to adult services. Without adequate preparation to move from paediatric services to adult services their health may suffer. In some cases young people may feel alienated by the new service and stop attending altogether, while others will not develop a rapport with the new service and not keep health professionals fully informed of their health status and requirements. While many of these problems are consistent with the changes all young people go through as part of adolescence and growing into adulthood, having chronic illnesses means the risks to their health and futures are even greater.

Many factors external to young people with chronic conditions have been identified as barriers to successful transition. There is no state-wide, coordinated system for transition in Victoria. This means that there is no planned transition from paediatric services where children are assumed to be dependent, have little or no knowledge about their condition and its management, to adult healthcare where it is assumed the patient has autonomy in decision making, is highly knowledgeable about their condition and its management and has the skills necessary to navigate the complexities of the system.³

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The Chronic Illness Alliance supports measures to ensure that young people make a planned, clear and thoughtful transition to adult services, with the objective of maintaining their medical care and quality of life. This requires preparation that begins long before the actual transfer takes place and includes education of the young person and their parents, knowledge of the young person's emotional needs and a sensitive process for introducing the young person to adult services.

The **LIFEs**pan Service Model¹ currently in practice in Toronto, Canada seeks to systematically and comprehensively prepare paediatric patients with chronic illnesses for their transition and subsequent transfer to adult care. The Chronic Illness Alliance recommends that a similar model be adopted by state-based health services in Australia.

In this model paediatric services change in response to the developmental stage of the child working on the basis that transition is an integral part of the whole process. It focuses on the patient's future by gradually preparing both patient and their family for adult life. At a certain stage paediatric and adult services share the young person's care. Both paediatric and adults services need far greater coordination with designated staff responsible for transition in order for this to be affective.

A *brief* explanation of this service model:

1. Growing Up Ready and the Shared Management approach².

There is a need to enable a shared responsibility framework for the management of patients with chronic illnesses among professionals, clients and their families. This framework or approach is known as **shared management**². Its aim is to enhance the ability of young people to self-advocate and work in consultation with their families and health professionals. In an increasingly ageing society where the service focus is likely to be on older adults with chronic illnesses, these frameworks aim to achieve optimal health outcomes for these young adults. Shared management refers to the therapeutic alliance between families and professionals that needs to be forged early. It is a planned, systematic approach to a gradual shift in responsibilities from the health care provider and parents to the young person, as developmentally appropriate. The result of shared management is a young adult who manages health care needs and who understands to the best of his or her ability that transition to adult services is a process.

Examples of shared management may include some of the following:

- Skill development
- Knowledge of condition and resources to assist in management of health care
- Being real and positive with families to develop shared hope and expectation for the future
- Start discussing this early
- Making sure that medical reports follow the patient at all times.

This approach formed the basis for the development of a series of resources by staff and families at Bloorview Kids Rehab. These are a series of three **Growing Up Ready** checklists designed to guide families in skill development and knowledge. A Timetable provides milestones to help families check their progress. At Bloorview Kids Rehab the ambulatory care nurses have taken responsibility for implementing this framework however all staff work towards helping clients to develop these skills and acquire knowledge about managing their health. The aim is to create a gradual shift of the responsibility of health care management from parent and health professional, to the young adult as is developmentally appropriate. The Growing Up Ready Framework was identified as a 'Leading Practice' at Bloorview's most recent Accreditation in September 2007.¹

2. Transfer Services

This comprises the *preparation for transition* clinic that assists adolescents (16+ years) and their families to consolidate these skills, gain knowledge and thus develop confidence as they prepare to move across to adult services. Most 16 year olds are referred into this clinic for a two-year preparation period. The team involved in this clinic is multidisciplinary and generally consists of a core team of the following disciplines: nursing, occupational therapy, social work, as well as a youth facilitator and a family facilitator who play a vital role at Bloorview in supporting the youth and family respectively. Medical care still continues as required but in other specialty clinics.

Transfer services also includes administrative processes that include summarising, coordinating and communicating and all documentation required to ensure that the receiving adult hospital *and the patient* have the information they require as they move to the adult system. This may also include a staff education component particularly for unusual or rare paediatric conditions.

3. Adult Services

This multidisciplinary clinic at the adult service includes staff that work across both paediatric and adult sites providing continuity of care. This clinic provides lifelong care for patients in collaboration with their General Practitioner, other specialists and local community supports. A

Nurse Practitioner and a Rehabilitation Physician work as members of the team and manage the patients within the scope of their respective practice.

Recommendations

- That paediatric services adopt a 'transition' approach that spans the whole of their care of children and young people with all chronic conditions;
- That adult and paediatric services develop a shared management approach;
- That greater cooperation between paediatric and adult services be undertaken to facilitate this approach.

References:

1. LIFEspan Service Business Plan Proposal-Bloorview Kids Rehab/Toronto Rehab - Dec 2007
 2. Gall, C., Kingsnorth, S., Healy, H. (2006) Growing Up Ready: A Shared Management Approach. *Physical and Occupational Therapy in Pediatrics*, 26(4), 47-62
 3. Kennedy A & Sawyer S (2008) Transition from pediatric to adult services: are we getting it right? *Curr Opin Pediatr.* 20 (4): 403-9
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