

# Transition care for young people – What should we be doing?

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As more and more young people with chronic illness survive into adulthood, transition from paediatric to adult health services has become an important consideration for young people, their families and health professionals. The process of transition is complex and can often be poorly coordinated. Young people may be unable to connect with appropriate services and may drop out with potentially dire consequences for their health outcomes.

Transition is the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from a child centred to adult oriented health system. Transition should be patient centred, flexible, responsive and coordinated. Successful transition should maximise quality of life through high quality, uninterrupted health care services.

Even though the importance of having a transition process is now well recognised, research indicates that health systems generally do not currently tackle the movement between paediatric and adult care well. There are a number of differences between paediatric and adult health care services and many young people find it difficult when they do not know in advance what to expect.

### *What are these differences?*

- Paediatric settings are family focused whereas adult services treat the young person as an independent adult and may not include the family.

- There is often more flexibility in the paediatric setting especially with appointments that accommodate family needs.
- Young people in the adult world will be expected to know about their medical conditions and take responsibility for self-care.
- There are often added costs to health care in an adult setting because paediatric hospitals are funded differently and many services are subsidised.
- There may be difficulty finding an adult health care provider trained in paediatric conditions.
- Families and paediatric staff may be unwilling to let go of the primary health care responsibility.

Discussions about transition should begin when a young person is about 13 years-old in order to allow enough time for planning. Important issues to consider are:

- selection of new health professionals
- how and when to say goodbye to the paediatric team, including how important medical information will be transferred
- selection of the adult facility
- guardianship issues/role of the carer if the young person is dependent
- money and equipment needs; billing, supply of medications and essential medical items and equipment
- availability of outpatient facilities
- young person's attainment and knowledge of their own needs.

In NSW, the Greater Metropolitan Clinical Taskforce's (GMCT) Transition Care Program was convened in December 2002 to provide a coordinated approach to improving systems and processes for young people with chronic illnesses and disabilities as they move from paediatric to adult health services. GMCT is funded by the NSW Department of Health. The Program Manager leads a team of three Transition Coordinators who are based at John Hunter Hospital in Newcastle, Royal Prince Alfred Hospital, and Westmead Hospital. These hospitals are affiliated with the three tertiary children's

hospitals (John Hunter Children's Hospital, Sydney Children's Hospital at Randwick and Children's Hospital Westmead). The program extends across all Area Health Services in NSW. The coordinators are critical to the success of the program. Their current focus is around:

- collecting data about the number and profile of young people who are currently using paediatric services, those that are planning to move to adult services and those who have recently made the move
- identifying gaps in transition services
- collaborating with clinicians, young people and their families to determine what processes and resources are needed to bridge the gaps
- developing resources for both young people and clinicians such as fact sheets, readiness for transition checklists and a website.

Consumer involvement is also a very important contributor to successful planning. All key Transition Care Committees have consumer participants including two young people who bring their personal experiences of living with chronic illness and disability to the program.

As part of its commitment to consumer input, the GMCT Transition Care Program recently held a forum for young people. The *Bringing in the Voices Forum* targeted young people aged between 16 and 25 who were preparing to move or had already moved from paediatric to adult health services. The forum explored questions such as:

- What does being a child/young person mean to you?
- What is it like being an adult?
- How does it feel being in transition?
- What are children's health services like for young people?
- How would you describe adult health services?
- How can we make adult services more youth friendly?
- What do young people need during the transition period?

Forum participants provided valuable suggestions on what they felt needs to be done to improve adult health services to make them more youth friendly. These included:

- improving the environment to make it more youth friendly
- showing respect, being caring and providing privacy for the young person
- educating staff on how to relate to and engage with young people
- including families when appropriate
- providing young people with more choice, and including them in making decisions about their care
- providing peer support

- improving communication so that all health professionals share information and the young person does not have to constantly repeat their history.

The results of the forum will be published and the suggestions used to inform future directions of the program. A forum for parents and carers is planned for later this year.

A national policy needs to be developed that clearly supports the need for a coordinated, systematic approach to transition care for young people from paediatrics to adult health care settings. If there are to be successful health outcomes for young people, the value of education of health professionals, patients and carers needs to be emphasised as well as the involvement of consumer advisory groups in the planning and development of an Australia-wide policy.

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*AWCH is a CHF member. For more information see [www.awch.org.au](http://www.awch.org.au).*

#### Bibliography

- American Academy of Pediatrics Policy Statement, *A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs*. Pediatrics Vol. 110 No. 6 December 2002, pp 1304-1306.
- Bennett DL, Towns SJ, Steinbeck KS, *Smoothing the transition to adult care*. MJA 2005; Vol 182 No 8, pp 373-374
- Blum RWM, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al (1993), *Transition from child-centred to adult health-care systems for adolescents with chronic conditions: A position paper of the society for adolescent medicine*. Journal of Adolescent Health, 14, 570-576.
- GMCT Transition Care Program, *Bringing in the Voices – Preliminary Report of the Transition Forum for Young People with Chronic Illness/Disability*. Unpublished. April 2005.