

Transition care – between a rock and a hard place?

¹S Khadr, ²C Kelnar

¹Specialist Registrar, Royal Hospital for Sick Children, Edinburgh, UK, and Member of the RCPE Transition Steering Group; ²Professor of Paediatric Endocrinology, Royal Hospital for Sick Children, Edinburgh, UK, and Chair of the RCPE Transition Steering Group

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Correspondence to CJH Kelnar,
Department of Paediatric
Endocrinology, Royal Hospital for
Sick Children, Edinburgh EH9 1LF, UK

tel. +44 (0)131 536 0611
e-mail chris@kelnar.com

More than 90% of children with chronic illness now reach adulthood and graduate to adult health services.¹ This generally occurs at a time of great change in their lives, both physical and emotional. Chronic illness has the potential to impact on young people's lives such that they risk being hindered in the achievement of developmental milestones.² Furthermore, puberty heralds increases in the prevalence of mental health problems and substance misuse, trends that are more pronounced in and may be more detrimental to young people with chronic illness.³

Transition has been defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents... with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems'.⁴ Young people with chronic illnesses must be supported in the transition to adulthood as they acquire the knowledge and skills to take responsibility for managing their own healthcare and keeping themselves well.

The concept of transition care has developed from examples of good practice that have evolved between adult and paediatric centres by serendipity or through the enthusiasm of individuals. At the same time, evidence has accumulated to suggest that the health of young people with chronic illnesses deteriorates and their engagement with health services lessens around the time of transfer to adult services.^{5,6}

In recognition that the process of maturing from childhood to adulthood is complex for young people, their carers and health providers, the Royal College of Physicians of Edinburgh has supported the development of a guidance document, *Think transition: delivering the essential link between paediatric and adult care*, which will be published imminently and is available online.² Generic issues discussed include how to foster growing autonomy, develop appropriate services and facilities and make best use of limited resources. Such considerations have wide applicability across different countries and healthcare systems worldwide.

Successful transfer from paediatric to adult services should be the culmination of a period of planned transition care. Transition has often been considered to be primarily paediatrically driven, but input from adult physicians is of great importance. There is evidence to suggest that involvement of adult healthcare professionals during transition may improve patient satisfaction, clinic attendance⁷ and/or health outcomes.⁶ Collaboration with adult healthcare providers to develop appropriate services for young adults is essential.

Young people have a right to expect age-appropriate, accessible services and high quality healthcare⁸ at every stage of their patient journey. As well as multiagency input in relation, for example, to education and employment issues, effective multidisciplinary working and communication between healthcare professionals and providers is crucial. Recent Government guidance has underlined the requirement to ensure that transition from paediatric to adult physician care is 'undertaken in a structured, consistent and well-understood manner which is fully centred on the patient's needs'.⁹ These needs are universal, even if how this is achieved in terms of practical service restructuring and resource implications will differ between healthcare systems.

One of the aims of transition is to support young people as they become responsible for making healthcare decisions previously taken by parents and others acting in their 'best interests'. There is now emerging evidence of the benefits of seeing young people on their own before transfer to adult services in terms of quality of life,⁹ patient satisfaction, successful transfer and feasibility.⁵ Nevertheless, it is important that parents are not marginalised during this process and are supported to accept their children's growing autonomy.

Education is key to empowering young people to participate more independently in their care. Training to improve understanding of, and participation in, their illness care, self-advocacy and negotiation skills is essential. Structured education programmes for young people in transition have been shown to improve clinic

attendance and may have an impact on illness control.⁶ Whilst much of this can be incorporated into routine outpatient service provision, various other means of delivering education should be explored to help foster young people's commitment to the process. Examples include multimedia options,³ involvement of youth workers or peers² and the active engagement of young people in designing their transition care programme. The views of young people are of great importance in deciding how services that affect their care should be developed.⁸ To this end, young people have been involved in developing the RPCE *Think transition* guidance.

Healthcare professionals looking after young people with chronic illnesses also need training in transition care. Certain aspects of this training are generic: the Age Appropriate Care Working Group is to recommend that all healthcare professionals working with young people in Scotland receive general training in adolescent health and development.¹⁰ Web-based training programmes such as the Adolescent Health Project developed by the Royal College of Paediatrics and Child Health¹¹ offer an inexpensive, accessible alternative to text-based resources. Other aspects of training will relate more specifically to transition or to the chronic disorder in question. There are examples of existing resources that could be adapted for use by other specialties for training in transition care.⁵

Young people from potentially marginalised groups present particular challenges for healthcare staff in terms of transition care, and specific solutions may be

required in their cases. Deprivation and/or social exclusion can have a significant impact on young people's health outcomes.⁸ Detrimental effects may be compounded by health services that are inaccessible, inflexible or lack an inclusive and/or culturally sensitive approach.² In these cases, the importance of effective communication,^{2,5} non-discriminatory attitudes, careful coordination of care and joined-up multiagency working is paramount.² Access to care locally is important¹² and, for those living in remote/rural areas, managed clinical networks may enable provision of high quality local transition care with support from specialist centres.

Key workers, who may be from a variety of disciplines and backgrounds, have been shown to make a positive difference to families' experiences of healthcare and may be especially useful where young people's needs are complex.² Models exist that provide a useful framework for training and implementation.¹³

Growing up presents challenges for all young people in today's society and can sometimes be difficult and turbulent. Those with chronic illnesses may be particularly vulnerable, and their needs during the transition to adulthood should be identified and addressed in a coordinated manner. The timing of transfer to adult services should be the culmination of a period of planned transition care and guided by the choice and physical, social and emotional maturity of the young person.^{14,15} The ultimate goal should be to embed transition care as a key part of adolescent health provision.

REFERENCES

- Viner R. Effective transition from paediatric to adult services. *Hosp Med* 2000; 61(5):341–3.
- Royal College of Physicians Transition Steering Group. *Think transition: developing the essential link between paediatric and adult care*. Edinburgh: Royal College of Physicians; 2008. Available from: <http://www.rcpe.ac.uk>
- Sawyer SM, Drew S, Yeo MS et al. Adolescents with a chronic condition: challenges living, challenges treating. *Lancet* 2007; 369(9571):1481–9.
- National Service Framework for Children, Young People and Maternity Services. *Transition: getting it right for young people*. London: Department of Health; 2006. Available from: <http://www.rch.org.au/emplibrary/transition/TransitionGettingitrightforyoungpeople.pdf>
- McDonagh JE. Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities. London: Department of Health; 2006.
- Nakhla M, Daneman D, Frank M et al. Translating transition: a critical review of the diabetes literature. *J Pediatr Endocrinol Metab* 2008; 21(6):507–16.
- Bent N, Tennant A, Swift T et al. Team approaches versus ad hoc services for young people with physical disabilities: a retrospective cohort study. *Lancet* 2002; 360:1280–6.
- Scottish Executive. *Delivering a healthy future: an action framework for children and young people's health in Scotland*. Edinburgh: Scottish Executive; 2007. Available from: <http://www.scotland.gov/Publications/2007/02/14154246/0>
- McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology* 2007; 46(1):161–8.
- Children and Young People's Health Support Group. *Draft report of the Age Appropriate Care Working Group of the National Steering Group for Specialist Children's Services*. Edinburgh: Scottish Government Health Department; 2008.
- <http://www.rcpch.ac.uk/Education/Adolescent-Health-Project>
- Remote and Rural Steering Group. *Delivering for remote and rural healthcare. The final report of the Remote and Rural Workstream*. Edinburgh: Scottish Government Health Department; 2008.
- Care Coordination Network. *Key worker standards*. York: Care Coordination Network; 2004. Available from: <http://www.ccnuuk.org.uk/skins/CCNUK/downloads/keyworker.pdf>
- Department of Health. *Getting the right start: National Service Framework for Children, Young People and Maternity Services. Part 1: Standard for hospital services*. London: Department of Health; 2003. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4006182
- Royal College of Paediatrics and Child Health. *Bridging the gaps: health care for adolescents*. London: Royal College of Paediatrics and Child Health; 2003. Available from: <http://www.rcpch.ac.uk/Publications/Publications-list-by-title>

Note: A fuller list of references for the statements in this editorial can be found in the RCPE *Think Transition* document at www.rcpe.ac.uk