# Effective transition from paediatric to adult services

*Russell Viner*

***The effective transfer of adolescents from paediatric to adult services is a new quality issue confronting all health services. This article reviews current knowledge in the field and outlines good practice.***

The efficient and caring transfer of adolescents from paediatric to adult care is one of the great challenges facing health professionals in the new century (Viner and Keane, 1998). Many conditions once thought to be purely the realm of paediatricians, such as cystic fibrosis, congenital heart disease and metabolic conditions, must now be thought of as diseases that begin in childhood but continue into adult life. Arranging effective transition of care is now a necessary part of caring for young people with chronic illness, and neither simple transfer to adult doctors nor allowing adolescents to 'drop out' of medical care is acceptable quality care in the 21st century. This article presents current good practice in transition for young people.

## BACKGROUND

The most useful definition of transition is the Society for Adolescent Medicine notion of:

> **'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems' (Blum et al, 1993).**

While some paediatric services in the UK have established good links with adult centres (Kurtz and Hopkins, 1996), there is widespread ignorance of the need for transition planning and a lack of guidelines on establishing transition services. The House of Commons Select Committee on Health (1997) emphasized that:

> **'Services for adolescents should be given greater focus and priority. The transfer of young people, particularly those with special health needs, from child to adult services requires specific attention.'**

Transition planning is most important for those with chronic illness. The burden of chronic illness in adolescence is increasing as larger numbers of chronically ill children survive into the second and third decades (Siegel, 1987; Newacheck and Taylor, 1992; Gortmaker and Sappenfield, 1984). The prevalence of cystic fibrosis in patients over 15 years of age in the UK more than doubled between 1977 and 1985 (British Paediatric Association Working Party on Cystic Fibrosis, 1988), and currently over 85% of children with chronic illness survive to adult life (Gortmaker and Sappenfield, 1984). This change from paediatric to adult care is often challenging for healthy young people as well as those with a chronic illness. Young adults often do not register with a GP (Donovan and McCarthy, 1988; Kari et al, 1997) and frequently drop out of the medical system after they leave home (Blum et al, 1993; Carroll et al, 1983; Schidlow and Fiel, 1990).

## PROBLEMS WITH TRANSITION

Where transition has not been planned appropriately, transfer of patients is often haphazard. Common reasons for transfer are leaving school, events such as pregnancy or a suicide attempt (Sawyer et al, 1997), and patient refusal to attend paediatric clinics any longer. In addition, young people may use a relatively healthy period to 'drop-out' of follow up. Sadly, too often non-adherence and difficult behaviour can result in a transfer to adult services out of desperation by paediatric professionals.

## OBSTACLES TO TRANSITION

Obstacles to transition can arise from many areas, including the young person and their family, but also from paediatric staff and receiving adult services. Paediatric staff are often unwilling to 'let go' and trust to the independence of the adoles-

**Dr Russell Viner** is Consultant in Adolescent Medicine in the Department of Paediatrics, Middlesex Hospital, London W1N 8AA

cent or the skills of the adult services (Schidlow and Fiel, 1990). Because of this, the paediatric team may give adolescents subtle cues implying distrust of the competence or commitment of adult staff which work to undermine the transfer process (Barbero, 1982). This is particularly so in rare congenital and metabolic disorders in which paediatricians see themselves as the best caregivers regardless of the age of the patient. The reduction in paediatric clinic numbers and a loss of long-term patient follow-up may have negative consequences for paediatric staff carrying out research, leading to patients remaining in paediatric clinics long-term (Schidlow and Fiel, 1990).

For young people themselves, transition can be a life event, involving losing respected and often loved carers and being forced to trust new and unknown staff. Moving to adult services may also be seen as taking a step closer to disease complications and even death, particularly in diseases such as cystic fibrosis and diabetes. Additionally, the families of young people may sabotage transition arrangements if they feel left out of decision-making in the new adult setting.

Adult services themselves frequently present obstacles to successful transition. Adult physicians may have little interest in ‘paediatric’ diseases in adult life and taking on extra patients with chronic illness may be a financial liability (Schidlow and Fiel, 1990; Sawyer et al, 1997). Adolescents often find busy clinics full of elderly sick patients very alienating, particularly if they seem to get short shrift from their new adult doctor who is more interested in the complicated older patients.

Hospital and management problems may be equally important deterrents to transition. Few hospitals even within the NHS have well-established and reliable communication channels for transfer of medical records and imaging results, often resulting in lost notes, miscommunications, contradictory advice and potential conflict.

## PRINCIPLES OF A GOOD TRANSITION PROGRAMME

Obstructions to transition are many; however, the development of a clear transition programme for each clinic can overcome many of the problems inherent in moving between two different systems. An effective transition programme requires the following key elements:

### A policy on timing of transfer

There is no ‘right’ time for transition and a flexible approach is most important. Timing must depend on the developmental readiness and health status of the individual adolescent as well as the capabilities of the adult providers (Blum et al, 1993). However, a target transfer age is useful for both staff and young people in anticipating and preparing for transition. Some clinics use a chronological cut-off (varying from 15–20 years of age in different clinics), others use social transitions such as leaving school.

Provided that paediatric services make an effort to cater for adolescents, transition should not occur until young people have largely completed the developmental tasks of adolescence, i.e. a transition target such as 18 years of age or school-leaving age is best. Earlier at 15 or 16 years of age, many with chronic illness will not have completed their growth or pubertal development and adult services are unlikely to pay attention to such changes. Additionally, many young people will quickly go on to many years of further education, requiring an immediate second transfer to adult services closer to their university or college.

### A preparation period and education programme

Transition should not occur before the young person is able to function in an adult clinic, i.e. before they have the necessary skills and education to manage their illness largely independent of parents and staff — skills they are unlikely to be taught in the adult clinic. To achieve this, preparation must begin well before the anticipated transfer time — preferably in early adolescence when a series of educational interventions should discuss their understanding of the disease, the rationale of therapy, the source of symptoms, the recognition of deterioration and the appropriate responses, and most importantly, how to seek help from health professionals and how to operate within the medical system (Bronheim et al, undated).

As part of this programme, young people should be helped to take responsibility for medication from as early an age as possible, and should be seen by themselves in clinic visits from the age of 13 years (with parents invited to join the session later). A schedule of likely timing and events should be given to young people in early adolescence, and young people should be involved in planning the timings of their own transition. Leaflets and material about the transition programme and details of the adult service should be provided in clinic settings from early adolescence. Additionally, young people should be given information on their health-care rights and effective ways of dealing with medical staff situations including casualty or waiting rooms.

### A coordinated transfer process

Around a year before the anticipated transfer date, adolescents should receive a detailed outline of the adult programme, and should undertake at least one visit to the adult clinic, preferably with parents and a trusted paediatric carer. A personal introduction to the adult environment and staff should be arranged, and at least one return visit made to the paediatric clinic to discuss any concerns before transfer. A joint paediatric–adult clinic is very useful to introduce adolescents to adult physicians and to handover clinical issues; however, a single joint clinic must not replace a coordinated transition programme (Court, 1993). Rather than a single joint clinic, the initial transfer of young people to formal 'young adult clinics' staffed by both paediatric and adult physicians may be the best method, particularly in diseases such as diabetes where the average age of the adult population may be very high.

A coordinated process requires a coordinator, and busy paediatricians may rarely have time to undertake this role. Clinical nurse specialists, if available, are best suited to run transition programmes in speciality clinics.

### An interested and capable adult service

A transition programme can only be successful if organized with the active participation and interest of the adult staff (which may be the clinical nurse specialists).

### Administrative support

Institutional and management support must be assured at both ends of the transfer chain. Casual agreements between doctors, while easy to set up, are prone to failure (Schidlow and Fiel, 1990). Resources such as administrative and secretarial support must be available to ensure the efficient organization of appointments and the transfer of medical records.

### Primary care involvement

Transition planning must involve primary care physicians, who may provide the only medical continuity for young people and their families during this time of change. It is a sad fact that many young people with chronic illness have little involvement with their GP (Carroll et al, 1983; Kelly, 1995).

## CONCLUSIONS

Transfer to adult care is a major life event for young people with chronic illness, and the appropriate management of this transition is an essential part of best practice in any paediatric clinic. Age and mode of transfer will differ according to locality and history; however, transition in midadolescence should be avoided. Programmes for adolescents should be developed in all paediatric services, and paediatricians should be prepared to care for young people up to school-leaving age if appropriate. Transition programmes are necessary even when paediatric and adult services are in the same hospital, as geographical closeness does not necessarily mean that there is a close professional relationship. **HM**

*Conflict of interest: none.*

Barbero G (1982) Leaving the pediatrician for the internist. *Ann Intern Med* **96:** 673–4

Blum R, Garell D, Hodgman C 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. *J Adolescent Health* **14:** 570–6

British Paediatric Association Working Party on Cystic Fibrosis (1988) *Report on Cystic Fibrosis*. British Paediatric Association, Leeds

Bronheim S, Fiel S, Schidlow D *Crossings: A Manual for the Transition of Chronically Ill Youth to Adult Care.* Pennsylvania Department of Health, Philadelphia

Carroll G, Massarelli E, Opzoomer A et al (1983) Adolescents with chronic disease: are they receiving comprehensive health care? *J Adolescent Health Care* **4:** 261–5

Court J (1993) Issues of transition to adult care. *J Paediatr Child Health* **29** (Suppl 1): 53–5

Donovan C, McCarthy S (1988) Is there a place for adolescent screening in general practice? *Health Trends* **2:** 64

Gortmaker S, Sappenfield W (1984) Chronic childhood disorders: prevalence and impact. *Pediatr Clin North Am* **31:** 3–18

House of Commons Select Committee on Health (1997) *Hospital Services for Children and Young People. Fifth Report.* HMSO, London

Kari J, Donovan C, Li J, Taylor B (1997) Adolescents' attitudes to general practice in North London. *Br J Gen Pract* **47:** 109–10

Kelly A (1995) The primary care provider's role in caring for young people with chronic illness. *J Adolescent Health* **17:** 32–6

Kurtz Z, Hopkins A (1996) *Services for Youth People with Chronic Disorders in Their Transition from Childhood to Adult Life.* Royal College of Physicians, London

Newacheck P, Taylor W (1992) Childhood chronic illness: prevalence, severity and impact. *Am J Public Health* **82:** 364–71

Sawyer S, Blair S, Bowes G (1997) Chronic illness in adolescents: transfer or transition to adult services? *J Paediatr Child Health* **33:** 88–90

Schidlow D, Fiel S (1990) Life beyond pediatrics. Transition of chronically ill adolescents from pediatric to adult health care systems. *Med Clin North Am* **74:** 1113–20

Siegel D (1987) Adolescents and chronic illness. *JAMA* **257:** 3396–9

Viner R, Keane M (1998) *Youth Matters: Evidenced-based Best Practice for the Care of Young People in Hospital.* Caring for Children in the Health Services, London

## KEY POINTS

- Transition preparation must be seen as an essential component of high quality health care in adolescence.
- Every paediatric general and speciality clinic should have a specific transition policy. More formal transition programmes are necessary where large numbers of young people are being transferred to adult care.
- Young people should not be transferred to adult services until they have the skills to function in an adult service and have finished growth and puberty.
- An identified person within the paediatric and adult teams must be responsible for transition arrangements. The most suitable persons are nurse specialists.
- Management links must be developed between the two services. Local commissioners must be consulted when patients are transferred from one tertiary centre to another.
- Evaluation of transition arrangements must be undertaken.