

Transitional care for young people with diabetes: When, where and how?

Emma Day

There has been much written recently (e.g. Fleming et al, 2002) and historically (e.g. Blum et al, 1993) about the importance of smooth transfer from paediatric to adult healthcare systems for young people who live with chronic conditions. In this article, Emma Day explores the 'when', 'where' and 'how' of this transfer and offers recommendations to help transitional care be a positive experience.

The negative feelings that young people with chronic conditions experience when transfer to adult care is poorly handled are well documented (Shaw et al, 2004; *Figure 1*).

As highlighted in the National Service Framework (NSF) for children, young people and maternity services (Department of Health [DoH], 2003a), 'the transfer of young people from child to adult services requires special attention.' Sadly, though, it is stated: 'Evidence shows that this is often poorly handled.'

A consensus from Blum et al in 1993 says:

'transition is a multi-faceted process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child to adult-centred care.'

More recently, healthcare professionals working in the UK caring for young people with type 1 and type 2 diabetes have had available an increasing number of documents that provide clear guidelines for the planning of this transfer (DoH, 2003a; DoH, 2003b; National Institute for Clinical Excellence, 2004). The NSF for children, young people and maternity services (DoH, 2003a) states:

'every paediatric general and speciality clinic should have a policy on transition to adult services which should be the responsibility of a named person.'

It is also stated that this should include:

- a policy on timing of transfer
- a preparation period and education programme
- a coordinated transfer process
- an interested and capable adult service
- administrative support
- primary healthcare and social care involvement.

The 'when', 'where' and 'how'

When the author was put in charge of writing and implementing a transitional care policy within Birmingham Children's Hospital (a large children's hospital providing care for 350 children and young people who live with diabetes) the challenges involved soon became apparent.

The 'when', 'where' and 'how' of this transitional policy for young people with diabetes – which are each linked to the 'why' – needed to be considered. (Some factors that might be involved are shown in *Table 1*.) Below, the author discusses these issues with particular regard to what happens at Birmingham Children's Hospital following the policy development.

Article points

1. The negative feelings that young people with chronic conditions experience when transfer to adult care is poorly handled are well documented.
2. There are a number of documents that provide clear guidelines for the planning of this transfer.
3. There are still many challenges involved in transitional care.
4. In particular, it should be remembered that one size does not fit all.

Key words

- Young people
- Transitional care
- Diabetes clinics

Emma Day is a Clinical Nurse Specialist (Paediatric Diabetes) and a Diabetes Home Care Coordinator, Birmingham Children's Hospital, Birmingham.

Table 1. Factors for consideration in transitional care policy.
<ul style="list-style-type: none"> ● Chronological age (age based on date of birth) ● Maturity, adolescent readiness and independence ● Medical adherence ● Availability of an adult specialist with appropriate training

The ‘when’

Standard 6 of the NSF for diabetes (DoH, 2003b) states:

‘all young people with diabetes will experience a smooth transition from paediatric diabetes to adult diabetes services [...] the transition will be organised in partnership with each individual and at an age appropriate to them.’

The question of whether there is a right chronological age to transfer young people to adult care has long been debated. For instance, the NSF for children, young people and maternity services (DoH, 2003a) states:

‘Although it may be useful to set a target age, there is no “right” time for transition. A flexible approach is called for that takes developmental readiness into account and links to other social transitions such as leaving school.’

It was agreed at Birmingham Children’s Hospital that an individualised transfer plan should be in place by the time a person reaches 14 years of age, although the process can and does start earlier than this. The provision of age-banded clinics has been in place for many years and they have been well received by young people.

The right age at which to transfer young people is led by many factors. Chronological age is

often more of an issue with designated children’s hospitals, which may have a trust policy on admission led by the child’s chronological age. In the case of the best time to consider transfer to adult services, many paediatricians and paediatric diabetes specialist nurses (PDSNs) are more likely to consider the young person’s level of maturity and independence, which may have little to do with chronological age in some cases (Fleming et al, 2002). Whether people are looking after themselves (including medical adherence) can be considered to help determine a timescale for transfer.

Young people often experience many issues at the time when transitional care and transfer is discussed. Some of the issues impacting on their lives at this time are educational and vocational (such as trying to find their way in the world and making decisions which are going to impact on their lives in terms of career choice or further education). With the need to establish their identity physically, personally, emotionally and sexually, these issues cause a great deal of angst among adolescents (Greene and Greene, 2005).

The introduction of a transitional care process could help with other challenges the young person faces, the author believes. An example of this is that at the time of change from primary to secondary education (around 11 years of age), young people are asked to take on more responsibility for many aspects of their school and social life. At this age, young people are by no means ready to look after all aspects of their diabetes, but, in the author’s opinion, it is an opportunity not to be missed, where socially and culturally they are maturing and expectations are high from parents, teachers and peers. The author and her colleagues take this opportunity at their clinic to direct diabetes management education towards the young people rather than their parents. This may also be the first opportunity to let young people know what the future holds for them in terms of their diabetes care.

Young people with diabetes cared for at Birmingham Children’s Hospital are transferred to adult care at some point after their 16th birthday, taking factors such as maturity and readiness into account. The timings for the majority of those transfers are based on four main

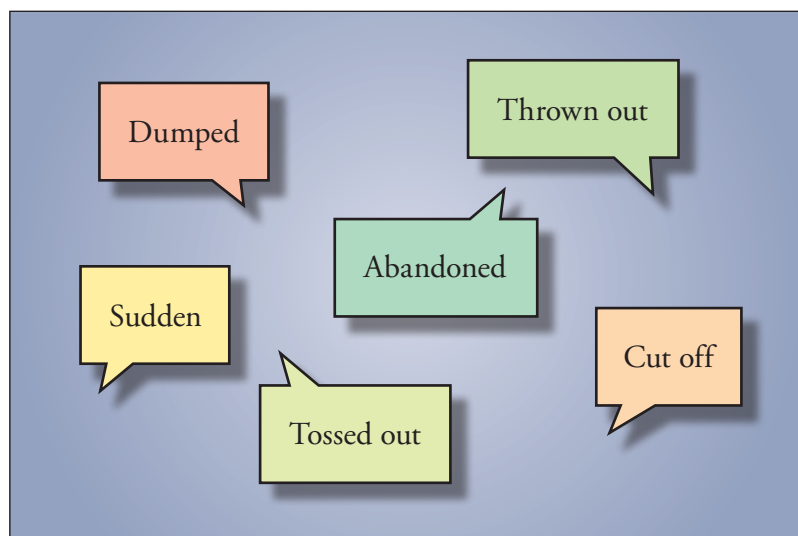


Figure 1. Examples of negative responses expressed when young people with chronic conditions are transferred to adult care (adapted from Shaw et al, 2004).

categories:

- 16 or older once full time education is completed
- 16 or older and remaining locally to undertake further education
- 16 or older following a year of work
- pregnant or married.

The average age of transfer from Birmingham Children’s Hospital to adult services during 2004 was between 17 and 18 years. Young people surveyed by Court (1993) anticipated the most appropriate age for transfer to be 17–25 years.

The ‘where’

One of the unique challenges faced by specialist children’s hospitals providing care for young people with chronic conditions is the need to access adult services from a multitude of providers. For instance, young people being cared for at Birmingham Children’s Hospital have up to six such hospitals available. To overcome this challenge, links were made with the author’s adult nursing and medical colleagues at two of these hospitals and young adult clinics were set up. The first was set up in 1994 and the second in 1998, after being able to identify interested and capable adult providers, which agrees with later-released guidance from the NSF for children, young people and maternity services (DoH, 2003a).

The ‘how’

Preparation for young people and their families is paramount if the process of transfer is to be a smooth one: ‘The patient should be a central participant in the planning and delivery of his/her care’ (Carson, 2003). At Birmingham Children’s Hospital, the process is discussed and planned, and a decision regarding hospital of choice is made up to 2 years prior to the final transfer (when care is completely handed over to the adult provider). This is to allow young people and their parents to feel some ownership of the process and to give them a real sense of choice.

In order to alleviate the fear of the unknown and in preparation for final transfer, a home visit is made by nurses and dietitians. During this visit, what to expect from adult care will be either outlined for the first time or, in most cases, discussed again. The particular hospital of choice

will have its own systems in place regarding how to access support and when it is available.

The Royal College of Paediatrics and Child Health (2003) eloquently describe adolescents as:

‘sitting poorly between the family centred, developmentally focused paediatric paradigm (which frequently ignores their growing independence and increasingly adult behaviour) and the adult medical culture which acknowledges patient autonomy, sexual health and employment issues but may neglect growth, development and family concerns.’

At Birmingham Children’s Hospital, these differences are highlighted and emphasis is put on the young person accessing care and support for themselves. This is often necessary because of the paternalistic approach of some paediatric care settings. Self-management and problem-solving techniques are discussed and a chance to practise these with a ‘safety net’ is offered during the time prior to eventual transfer of care.

How the young adult clinic might run, differing aims of control for adults with diabetes, and screening for and avoidance of complications are all topics that continue to be discussed.

Carson (2003) highlights the importance of building and maintaining relationships with young people with diabetes and the need for there to be some consistency in the personnel providing and coordinating their care during this time.

Page points

1. Preparation for young people and their families is paramount if the process of transfer is to be a smooth one.
2. Carson (2003) highlights the importance of building and maintaining relationships with young people with diabetes and the need for there to be some consistency in the personnel providing and coordinating their care during this time.

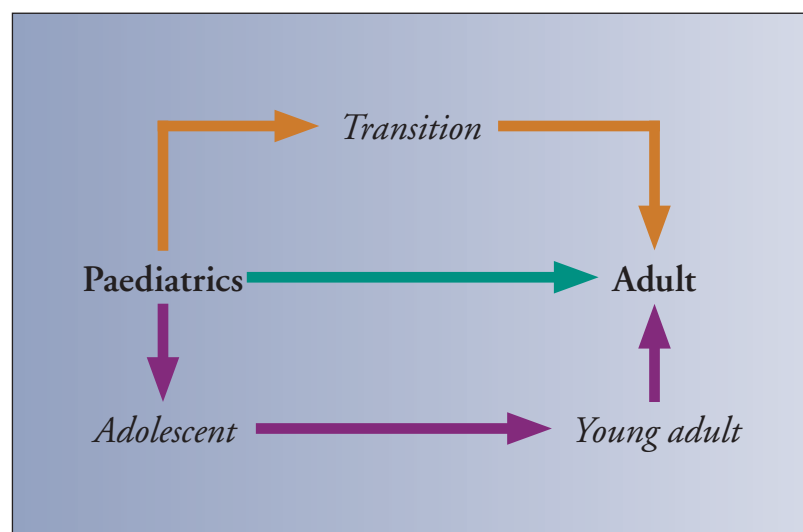


Figure 2. Three possible transitional care models for young people.

Page points

1. In some district general hospitals, a care model with a transitional stage can be adopted where care can be shared until the young person feels ready to transfer over to adult services completely.
2. For specialist children's hospitals, the best pathway may be from the adolescent clinic, through the young adult clinic, and onto the adult clinic.
3. While there is universal agreement that there should be robust and specific policies on transitional care, it should be remembered that one size does not fit all.

Recommendations.

- 1 Develop a written policy on transfer and transitional care.
- 2 Put together a personalised plan for young people, taking into account their cultural, social, emotional, medical and physical needs.
- 3 Work in partnership with young people and families to give real choice of future care provision.
- 4 Take into account the need for liaison and communication between paediatric care providers and capable, interested adult care providers.

The first attendance at the young adult clinic needs to be a positive experience to avoid 'drop out', the author believes. At Birmingham Children's Hospital, in order for the first visit to be as smooth as possible, a medical letter of referral is sent out that details diagnosis and history of control and admissions and also includes psychosocial history. To ensure that familiar faces are at the clinics, the PDSN and consultant attend all young adult clinics. Young people surveyed by Court (1993) commented that they valued continuity of care in terms of personnel.

Prior to each young adult clinic, the PDSN identifies any first-timers to introduce them to the clinic experience. In addition, young people are encouraged to maintain contact with the PDSNs with whom they are familiar, and, prior to their first appointment, to let their adolescent care team know when the appointment is.

Where there is a choice made to go to an adult provider with no joint clinic (a clinic with a PDSN present), a PDSN makes personal contact (usually by telephone) with the diabetes specialist nurse to identify the young person to him or her.

Case studies

It is with the issues discussed above in mind that three case studies are presented (*Appendix 1*) to highlight some of the challenges that have been met when planning transitional care for young people with diabetes.

Models of transitional care

The various models of transitional care depicted in *Figure 2* lend themselves well to different types of care provision, as exemplified below.

District general hospitals

If providing care for young people within a district general hospital where there are paediatric and adult services based on the same site and interested individuals can be identified, a care model with a transitional stage can be adopted where care can be shared until the young person feels ready to transfer over to adult services completely.

Specialist children's hospitals

The model that lends itself best to specialist children's hospitals, the author believes, is the

pathway from the adolescent clinic, through the young adult clinic, and onto the adult clinic when the individual is ready and able. This works well if personnel from both paediatric and adult teams are able to support the clinics and provide individual-centred approaches to young people's care.

Conclusion

While there is universal agreement that there should be robust and specific policies on transitional care provision for all young people with chronic conditions (e.g. DoH, 2003a), it should be remembered that one size does not fit all, and individualised planning is essential if transitional care and transfer is to be a positive experience. The aim to keep adolescents and young adults 'in the system' is of paramount importance; this is only achievable if transitional policies and philosophies of care exist. ■

Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB (1993) Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *The Journal of Adolescent Health* 14(7): 570-6

Carson C (2003) Adolescence to adulthood: how to keep adolescents in the system. *Journal of Diabetes Nursing* 7(1): 24-7

Court JM (1993) Issues of transition to adult care. *Journal of Paediatrics and Child Health* 29(Suppl 1): S53-5

Department of Health (DoH; 2003a) *National Service Framework for children, young people and maternity services: Standard for hospital services*. DoH, London. Available at <http://www.dh.gov.uk/assetRoot/04/06/72/51/04067251.pdf> (accessed 05.04.2006)

DoH (2003b) *National Service Framework for diabetes: Standards*. DoH, London. Available at <http://www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf> (accessed 05.04.2006)

Fleming E, Carter B, Gillibrand W (2002) The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. *Journal of Clinical Nursing* 11(5): 560-7

Greene S, Greene A (2005) Changing from the paediatric to the adult service: guidance on the transition of care. *Practical Diabetes International* 22(2): 41-5

National Institute for Clinical Excellence (NICE; 2004) *Diagnosis and management of type 1 diabetes in children, young people and adults*. Clinical Guideline 15. NICE, London. Available at <http://www.nice.org.uk/page.aspx?o=213575> (accessed 05.04.2006)

Royal College of Paediatrics and Child Health (RCPCH; 2003) *Bridging the Gaps: Health Care for Adolescents*. RCPCH, London. Available at www.rcpch.ac.uk/publications/recent_publications/bridging_the_gaps.pdf (accessed 05.04.2006)

Shaw KL, Southwood TR, McDonagh JE; British Paediatric Rheumatology Group (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey. *Rheumatology* 43(2): 211-9

Appendix 1. Three case studies highlighting some of the challenges when planning transitional care for young people with diabetes.

Case study 1: Jaye (pictured)

- Has Down's syndrome
- Has type 1 diabetes
- Became acutely unwell aged 5 years
- Two siblings help with her care
- Most of her caring is done by her mother
- Has built up close relationship with diabetes team over 14 years
- In a young adult clinic, would be seen by paediatric and adult teams, but her mother was very reluctant for her to transfer to a young adult clinic, because of the trust in the team Jaye knew
- Is still in full time education (at college)
- Functions at an above average level for a person with Down's syndrome
- Makes choices if facts explained

Solution

- Visit arranged to young adult clinic with paediatric diabetes specialist nurse (PDSN) and her mother
- Detailed transfer letter sent 6 months before transfer
- Final visit to paediatric clinic arranged after second young adult clinic appointment
- Access to 24-hour helpline provided

Case study 2: Jason

- Diagnosed with type 1 diabetes aged 9 years (in 1994)
- Lots of parental support provided
- Has always had good diabetes control (HbA_{1c}, 5.6–8.6%)
- In September 2004 went to university to study medicine, and continued to attend the adolescent clinic at Birmingham Children's Hospital
- In March 2005 requested transfer to adult clinic local to family home



Jaye (described in case study 1)

Case study 3: Daniel

- Diagnosed with type 1 diabetes aged 12 years (in 1998)
- Initially in paediatric clinic and well supported by parents
- Moved to adolescent clinic aged 14 years; immediately began to attend this alone and later attended with girlfriend
- Left school aged 16 years (in 2002) to start work in a restaurant
- In March 2003 discussed adult care options at the clinic and at home
- Also in March 2003 changed to multiple daily injection regimen
- In mid-to-late 2003 moved out of home, saw his relationship with girlfriend end and dropped out of part-time college
- In 2004 attended the clinic regularly to see PDSN for support and to work towards transfer to adult care; diabetes control was poor
- In 2005 attended young adult clinic; supported by PDSN and introduced to adult diabetes specialist nurse to continue accessing support

'The aim to keep adolescents and young adults "in the system" is of paramount importance; this is only achievable if transitional policies and philosophies of care exist.'