

Review of transitional care for young people with diabetes

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Article points

1. The diabetes self management skills gained during adolescence form the foundation of the individual's long-term ability to avoid complications; thus, it has a cost implication for the NHS.
2. Maintaining clinical contact with young people during the adolescent transition period is important for improving health outcomes both during adolescence and adulthood.
3. Peer support, age appropriateness of transition, retaining parental interest, communication and user involvement are all important factors in good transitional care services.

Key words

- Transitional care
- Adolescents
- Parental involvement

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Various national guidelines and recommendations have been published regarding age-appropriate transitional care for adolescents (see *Box 1*). However, this age group continues to consistently demonstrate poor control and outcomes in relation to both paediatric and adult age groups. For example, Kipps et al (2002) report that two years after transfer to the adult clinic attendance rates declined from 94 % to 57 % and Bryden et al (2003) demonstrated a significant increase in poor clinical and psychiatric outcomes during the transition period. This article looks at which factors contribute to a successful transitional diabetes care service.

Adult and paediatric diabetes care differ substantially. A child's diabetes management has input from their parents and during adolescence further responsibility passes from the parent to the teenager. The diabetes team aims to transfer individuals from paediatric to adult services with minimum disruption, but adolescence can be a time of difficulty, during which young people can become lost to the service and not re-present until complications – often avoidable with appropriate clinical support – have arisen (DoH, 2007).

The self-management and empowerment gained during adolescence forms the foundation of long-term abilities (Viner and Barker, 2005) and therefore have cost implications for the NHS: if an adolescent fails to implement appropriate self-management skills, outcomes are poorer and there can be increased healthcare costs during adulthood.

A supported transitional care programme can improve glycaemic control, reduce DKA

and hospital admission rates, maintain good clinic attendance in the long-term and produce cost savings via reduced admissions (Holmes-Walker et al, 2007).

A summary of the challenges

Growth spurts and hormonal changes profoundly effect development, psychological and physiological functions and diabetes control (Greene, 2001; Faulkner, 2003). The DCCT (1994) demonstrated that even with intensive treatment, the HbA_{1c} of adolescents was, on average, 1 % higher than that reported in adults. Additionally, peer pressure and rebellious behaviour sometimes results in serious diabetes complications, including death and cognitive impairment (Bryden et al, 2001).

Many young people can find the transfer to adult services a negative experience, with up to 52 % requesting another transfer to a different clinic (Busse et al, 2007). Negative opinions of the system could come from inadequate information about the transfer (Datta, 2003).

Bryden et al (2003) have shown just how poor outcomes can be in terms of clinical and psychiatric complications after the transition to adult diabetes services: the number of individuals with serious complications rose from 3% to 37% and the proportion with psychiatric disorders increased from 16% to 28%.

Recommendations

Recommendations from the Department of Health, the Royal College of Nurses and NICE for diabetes transitional care are shown in *Box 1*.

Solutions

Peer support

During childhood, people with diabetes are aware of long-term complications, yet by adolescence the majority have not experienced any. While long-term complications act as powerful stimuli to the parents of young people with diabetes, it may have the opposite effect on adolescent motivation, leading to a feeling of invincibility and a false sense of security.

One solution to motivating young people was proposed by Cuttell et al (2005), who successfully harnessed peer support and social activities to provide practical education for transition of diabetes care during a residential weekend. Introducing teenagers with poor diabetes control to peers who have developed complications can be beneficial in reinforcing the realities of long-term diabetes complications.

Retaining parental interest

Retaining parental involvement, while thought by some to be contrary to adolescents developing independence, produces improved glycaemic control during this period (Satin et al, 1989; Anderson et al 1999). Poor transitions can result from inadequate preparation and adolescent–parental conflict (Reisse et al, 2005; Silverstein et al, 2005). Conversely, too much responsibility too soon increases risks of psychological problems and eating disorders and many young people appreciate a degree of family, peer and teacher support in the

management of their diabetes (SIGN, 2001; Burke and Dowling, 2007).

Transition standards

German and Italian studies recommend transfer prior to age 20 years and never at times of education examination (Lausch and Reincke, 2004; Vanelli et al, 2004). The UK has transitional standards (*Box 1*) but current literature describes these as not being universally enforced and still requiring major development (Fox, 2002; Por et al 2004).

Communication

Transitions need pre-planning from the diabetes team, the young person with diabetes and their parents with the point of transfer to adult services individually negotiated and incorporating joint paediatric–adult clinics (Viner, 1999; McGill, 2002; Vanelli et al, 2004).

Franklin et al (2006) have shown use of modern communication technology, such as text messaging, as part of the diabetes care support package successfully improves young people’s self-efficacy and adherence to diabetes targets.

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1. Introducing teenagers with poor diabetes control to peers who have developed complications can be beneficial in reinforcing the realities of long-term diabetes complications.
2. Retaining parental involvement, while thought by some to be contrary to adolescents developing independence, produces improved glycaemic control during this period.
3. Transitions need pre-planning from the diabetes team, the young person with diabetes and their parents with the point of transfer to adult services individually negotiated and incorporating joint paediatric–adult clinics.

Box 1. Guidelines and recommendations for diabetes transitional care.

DoH National Service Frameworks (2001 and 2004)	All young people should have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood and they should have an individually planned and co-ordinated transition. A planned, smooth transition reduces drop-out rates.
DoH (2006)	Transition should be a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems. Maintaining clinical contact during adolescence improves both adolescent and adult health outcomes. Young people should be supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.
RCN (2004)	Achieving a seamless transfer is important.
NICE (2004)	Inform teenagers of changes in glycaemic targets and screening, hold joint paediatric–adult clinics 3 to 4 times per year and transition during a period of relative stability co-ordinated with other life transitions.

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1. Improving involvement in the design of these services could in turn improve the outcomes of the people who use the service.
2. The diabetes clinic at Bishop Auckland, County Durham, adolescent diabetes clinic service users were interviewed, taken to visit Ragnar Hanas' clinic in Sweden and asked to use the experience to make recommendations to be used to develop the Bishop Auckland clinic.
3. A transitional care framework and protocol aimed at providing young people and their parents with requisite knowledge, skills and confidence for successful transition were introduced at James Cook University Hospital in Middlesbrough.

User involvement

In developing improved transitional services there is sometimes a lack of user involvement and improving involvement in the design of these services could in turn improve the outcomes of the people who use the service (Dovey-Pearce et al, 2005). Studies have shown that young people with diabetes value the following in their care services (Court, 1993; Dovey-Pearce et al, 2005).

- Staff consistency.
- Courteousness.
- Easily manageable clinics.
- Provision of age-specific information.
- Support for health, emotional, social and developmental needs.
- Continuity of care.

Models from other areas of care

Issues of adolescent transition are not condition specific, but generic to all chronic childhood conditions, including mental ill-health and learning disabilities. It is therefore possible to learn from other areas of healthcare, including juvenile arthritis, congenital heart defects and cystic fibrosis (David, 2001; Reid et al, 2004; McDonagh et al, 2006).

Examples of good practice

The Bishop Auckland diabetes clinic

At the Bishop Auckland diabetes clinic, County Durham, adolescent service users were interviewed, taken to visit Ragnar Hanas' clinic at Uddevalla Hospital in Sweden and asked to use the experience to make recommendations to be used to develop the Bishop Auckland clinic (Bell et al, 2003).

The layout and décor of the clinic was designed by the adolescents who used the service. Parents or friends can attend clinic with the young person with diabetes. On arrival to the clinic the young person writes their name on the wallboard and indicates on a tick-grid the professionals they wish to see.

The young person with diabetes stays with the adolescents' clinic until they feel ready to transfer to the adult clinic – usually when they start work or university. This is generally around 18 years of age but can be up to 20

years or later still for individuals with learning difficulties. Non-attendees are frequently followed up and, unlike in some adult clinics, the staff never give up trying to contact them. Many non-attendees may have poor control, families offering no support or claim to simply be too busy to attend clinic.

There have been clear positive clinical outcomes in terms of improved HbA_{1c}, reduced numbers of DKA episodes (60 episodes per annum to 13 episodes per annum), a reduced number of serious hypoglycaemic episodes (115 per annum down to 10 per annum) and there has been a reduction in the number of non-attendees when adolescents are involved directly in their care options and decisions.

James Cook University Hospital

Following questionnaire results from young people's reviews of transition, Kelly Rowe, a Paediatric DSN at James Cook University Hospital in Middlesbrough, and her team found young people with diabetes inadequately equipped on transfer to adult services and set about changing that experience. They developed a clinical pathway for diabetes transitional care based on RCN adolescent transitional care guidelines. A transitional care framework and protocol aimed at providing young people and their parents with the requisite knowledge, skills and confidence for successful transition were introduced and are now on trial.

Transitional preparation consists of 3 stages: early stage (initiated at age 12 years), middle stage (14–15 years old) and late stage (15–17 years old). There are 6 key competencies:

- self-advocacy
- independent healthcare behaviour
- sexual health
- psychological support
- education and vocational planning
- health and lifestyle.

Each competency consists of individual developmentally appropriate tasks. Competencies are demonstrated in many ways both formally and informally, at clinic, during telephone conversations and in social events.

Group educational sessions are held for

specific subjects, including starting college or work, alcohol, drugs and sex. The young people also meet the adult diabetes team during these sessions and discuss differences between children's services and the young people's service.

There are two joint transfer clinics: the last children's clinic and first young persons' appointment, both of which are attended by healthcare professionals working in paediatric and adult services who provide individual, detailed transfer letters for official handover. The diabetes teams also attend an annual 'Goodbye and Hello' social evening for those who have recently transferred services or are about to. Finally, telephone feedback questionnaires before and after transition evaluate the process and inform future actions. Non-attendees are chased until contact is re-established during this period and transfer never occurs before GCSE examinations. For adolescents who have not achieved all competencies, the young persons clinic, aware of the gaps, continues to work on achieving them.

By working on transition from age 12, the process becomes a natural part of 'growing up' with the child, therefore achieving smooth, planned transition, fulfilling criteria shown to be the ingredients of a successful transition.

Ongoing audits of the service via formal feedback from young people and the evaluation of the young person from the adult clinic show that levels of self-management and coping and questioning skills are improving year-on-year. This is encouraging as the area has a high incidence of diabetes.

Conclusion

Recommendations for practice are shown in *Box 2*.

There is a lack of pre-planned, negotiated and supported transitional care for young people with diabetes and this, in addition to transferring to adult services at too early a developmental stage or failing to involve parents, can result in failure to attend clinic sessions (Viner, 1999; Kipps et al, 2002; McGill, 2002; Holboth and Norgaard,

2005). This can cause negative health outcomes and ultimately increase the number of people with diabetes who have clinical complications.

Attending their diabetes clinic appointments may help a young person maintain better glycaemic control and identify and treat problems earlier. Contacting all non-attendees should be mandatory; especially as anecdotal evidence suggests adult clinics have neither time nor staff to do this.

'Punishment transfers' of difficult cases from the young persons' to adults' services should not occur. These are where troublesome and poorly managed teenagers are transferred to an adult clinic as soon as they have reached the minimum age to qualify for the adult clinic. Once transferred, the individual will no longer be admitted to the children's ward. If anything, such young people should be retained in young people's clinics until they are better able to self-manage their diabetes. This is important for later health as behaviour problems in adolescence are an important influence on

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2. Attending their diabetes clinic appointments may help a young person maintain better glycaemic control and identify and treat problems earlier.
3. Simple discharge or transfer from paediatric to adult services is not the best option for all adolescents, neither is it best for a healthy future for young people, the health care team and the NHS budget.

Box 2. Recommendations for practice.

- All adolescents should have access to joint paediatric and adult transitional clinics.
- Parents should remain involved throughout the transition period.
- The traditional emphasis on transfer at aged 16 years should be changed: the worst time for transferring is during the stressful Year 11 GCSE examination and coursework year.
- Adolescents who miss appointments to be persistently followed up and not become lost to the service.
- Use of modern technology to aid communication.
- Adolescent's diabetes knowledge, self-management and coping skills be reviewed and updated; adolescent-specific education provided.
- Use of evaluation and feedback to ascertain what works and what does not.
- Use of a formal diabetes transitional care pathway as demonstrated by the James Cook University Hospital team.

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glycaemic control later in life (Bryden et al, 2001).

Simple discharge or transfer from paediatric to adult services is not the best option for all adolescents, neither is it best for a healthy future for young people, the health care team and the NHS budget. ■

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