

Smoothing the transition from paediatric to adult services in type 1 diabetes

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Article points

1. Adolescents with diabetes have specific health needs relating to the physical, emotional and psychological changes they are experiencing.
2. Clinic appointments are more likely to be missed as young people move from paediatric to adult services.
3. Up to 40% of young people with type 1 diabetes have microvascular complications by 18 years of age.
4. Before 2002, 40% of young people with diabetes in Newcastle did not attend specialist clinics; the establishment of a purpose-designed young adult clinic has achieved 84% attendance.
5. There is high uptake of psychological services in this age group.

Key words

- Type 1 diabetes
- Young adults
- Transition
- Attendance
- Psychology

Authors' details can be found at the end of this article.

During adolescence, young people with type 1 diabetes make the transition from parental control of their diabetes to independence, and a similar transition in the social aspects of their life. Studies have shown that many of them are already developing microvascular complications (Bryden et al, 2003). Most paediatric services in the UK provide care until the ages of 16–18 years, forcing the move to adult services at a time of high risk and instability. This article discusses the experience of the Newcastle Diabetes Service in trying to smooth the transition from paediatric to adult diabetes services through the provision of a joint transition clinic, followed by a young adult clinic. The impact of the young adult clinic on attendance rates and outcomes is examined.

Moving from childhood through adolescence into adulthood with type 1 diabetes is a complex process associated with high risk. Studies of adolescents and young adults with diabetes have shown that many of them are already developing microvascular complications (Bryden et al, 2003). During this period, the young person is making the transition from parental control of their diabetes to independence, and a similar transition in the social aspects of their life. In the UK, most paediatric services provide care until the ages of 16–18 years, forcing the move to adult services at a time of high risk and instability.

An audit of diabetes care in young people in the Trent region in 2003 revealed a huge variation between centres for both clinic attendance rates and complication screening rates (Wills et al,

2003). The highest attendance rates were obtained for the centre offering evening appointments and telephone reminders.

Standard 6 of the National Service Framework for Diabetes (Department of Health, 2001) specifies that:

“All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community based, either directly or via a young people’s clinic. The transition will be organised in partnership with each individual and at an age appropriate and agreed with them.”

This article discusses the experience of the

Newcastle Diabetes Service in trying to achieve these ideals through the provision of a young adult clinic. The impact of the clinic on attendance rates and outcomes is examined.

The Newcastle young person diabetes service

Newcastle has a large regional paediatric diabetes clinic with a population of approximately 250 children. Before 2002, young people with diabetes were referred to the adult clinic at around 18 years of age. An audit in 2002 revealed that 40% of young people with type 1 diabetes discharged from the paediatric service in the preceding 5 years were not attending an adult clinic.

In 2002, a two-stage transition was designed. It comprised a year of a joint transition clinic, with paediatric teams and adult teams working together, followed by a young adult clinic.

The evening young adult clinic at Newcastle Diabetes Centre is held monthly. The team consists of a consultant diabetologist, a DSN, a specialist registrar, a specialist dietitian and a clinical psychologist. Each healthcare professional has a special interest in adolescent diabetes, and continuity of care is achieved through minimal rotation of staff.

Background to clinic structure

“The success of transition between paediatric and adult services depends upon the relationship between these two teams [paediatric and adult] and, in addition, the preparation of the young people during this period.”

(Department of Health and Child Health and Maternity Services Branch, 2006)

Guidelines on the management of type 1 diabetes (NICE, 2004) recommend that paediatric diabetes teams organise age-banded clinics for young people jointly

with their adult specialty colleagues. They suggest that young people should be given time to familiarise themselves with the practicalities of the transition from paediatric to adult services. This is thought to improve clinic attendance, which is crucial as regular attendance is associated with improved glycaemic control, and provides the ability to screen for complications (NICE, 2004).

A transition clinic for 17 to 18 year olds is held three times a year. It is located within the adult service premises, and involves both paediatric and adult multidisciplinary teams. The protocol currently in place is for young people to have their last three visits as joint consultations, so that they can familiarise themselves with their new surroundings and team of healthcare professionals, before transfer to the young adult clinic.

The majority of these young people transfer to the adult services as a group at 18 years of age. However, as NICE (2004) suggests, there are exceptions to this rule:

“Age of transfer to the adult service should depend on the individual’s physical development and emotional maturity and local circumstances.”

Designing the clinic: Use of a focus group

The structure of the young adult clinic was initially designed, and continues to evolve, through service user involvement. A focus group with young people who are due to transfer from paediatric to adult services is held annually. Design features identified by the young people include:

- Evening clinics.
- Multidisciplinary team facilitators with the same staff members for each clinic.
- No additional visits for educational purposes.
- Informal group discussions within clinic time.
- Four-monthly appointments.

Page points

1. Working with young people can be challenging, and all members of the diabetes team need to be able to communicate effectively with young people.
2. It is important to inform young people preparing to move from paediatric to adult services that some aspects of their diabetes care and self-management will change.
3. These changes relate to understanding their own involvement in their diabetes management, targets for glycaemic control and screening for complications.
4. Young adults are often unwilling to spend time attending group structured education, so group discussion must be incorporated into their established clinic visits.

Fitting in with the working day

An out-of-hours clinic was requested by focus group participants, so that it would 'fit in' with the working day or student day, reduce waiting times and, perhaps most importantly, enable them to avoid sitting with older people who may have developed complications of diabetes – a major issue for some young people, as identified during the focus group.

Continuity of care and choice of healthcare professional

At their initial visit to the young adult clinic, the young person will meet each member of the team again, having met them previously in the transition clinic. During subsequent visits they can choose to see only one particular member of the diabetes team, depending on their individual needs; the exception being annual review when medical assessment is required.

Three appointments per year are provided to accommodate annual review, follow-up and education. This non-medical model is valued by young people as it allows them to access the healthcare professional with whom they feel they have the best rapport.

Following each appointment, a letter summarising the outcomes of the clinic visit and the agreed plan is sent directly to the young person and copied to his or her GP.

Working with young people can be challenging, and all members of the diabetes team require the skills to communicate effectively with them. NICE (2004) highlights the importance of informing young people preparing for the transition to adult services that some aspects of their diabetes care and self-management will change. These changes relate to:

- Understanding their own involvement in their diabetes management.
- Targets for glycaemic control.
- Screening for complications.

It is vital that DSNs working with young people forge good and honest relationships with them to put them at ease, so that they feel they can discuss any issue they choose and can contact the service for support. A non-judgemental approach to attitudes and approaches to self-care can enhance these relationships.

The majority of young people initially come to the clinic with a parent, although within a short period of time this changes, and they either come alone or with a friend or partner. A challenging aspect of working with this age group is the accountability of care; that is, the giving of knowledge and skills to inform choice when the individual does not want to listen or does not feel ready to take responsibility for his or her diabetes.

Opportunity for dietetic intervention

A lot of the food and eating habits we carry throughout our lives are developed in childhood and adolescence. Adolescence is often a transitory period of great change in attitude and lifestyle approach to diet. There are a number of reasons for this, for example leaving home for the first time and managing diabetes around working hours or shifts. Often, the first thing that suffers in a changing lifestyle is dietary management, disrupting a cornerstone of good glycaemic control.

Even from a dietetic perspective, the aim of the health professional is primarily to engage with the young person in order to establish a non-judgemental working environment of trust and empathy, from which positive outcomes are more likely. This is especially important with young females, as, in our experience, some often use their diabetes as a way of controlling their weight.

Group working: Engaging with young adults

One of the dietetic approaches is to generate group discussions around various food-related topics. The structured education programmes for carbohydrate counting offered to older adults with type 1 diabetes in our area were not well attended by the 18–23 years age group. In consultation, the young adults made it clear that they were not willing to commit additional time to attend group structured education sessions. It was therefore concluded that the benefits of group discussion must be incorporated into their established clinic visits.

Group work has been undertaken around common themes such as starting university, engaging in sporting activities, going travelling, carbohydrate counting and weight management.

Table 1. Use of the clinical psychologist in the young adult clinic.

Total no. of referrals since Nov 2006	No. seen for psychological assessment	No. seen more than once for psychological intervention
38	28	21

Psychological assessment and support

Psychological factors are of crucial importance in young adults' control of diabetes. A significant proportion of people with diabetes experience psychological problems (Pitts and Phillips, 1998). Eating disorders are common in late adolescent and young adult women in Western countries (Striegel-Moore, 1993). These conditions are of particular concern in young women with type 1 diabetes because of their association with impaired metabolic control and an earlier-than-expected onset of diabetes-related complications (Rydall et al, 1997). Specific aspects of diabetes and its management, for example weight gain associated with initiation of insulin treatment or improved metabolic control, and dietary restraint, may trigger the body dissatisfaction and drive for thinness that accompany eating disturbances (Nielsen and Mølbak, 1998).

The overwhelming majority of young adults want psychological care and recognise its benefits (Hixenbaugh and Warren, 1998). There is evidence that self-efficacy, a belief in one's own capacity to perform behaviour, is a useful concept in understanding control in people with diabetes (Hixenbaugh and Warren, 1998). The model employed within our service recognises the need to consider the individual person's perspective. A non-threatening approach is used, whereby the psychologist is present during initial clinical consultations, and can be introduced to the young person to initiate further intervention if required.

Table 1 shows the number of young adults who have been assessed by our clinical psychologist as a result of the clinic. As can be seen, a high number of these have gone on to have further contact and structured work with the psychologist.

Contraception and pregnancy planning

Young women with diabetes need to be aware that tight glycaemic control before, and during, pregnancy reduces the incidence of foetal loss and abnormality.

It has become clear to us that these young women are receiving conflicting contraceptive advice. Between 2004 and 2007, there have been six unplanned pregnancies among the young women attending our clinic. Following consultation with the sexual health department, a diabetes-specific guidance leaflet has been developed, which discusses the pros and cons of the various contraceptive methods. As part of our integrated contraceptive advice pathway, drop-in referrals are taken by the family planning clinic adjacent to the diabetes centre on the same evening of the clinic.

Evaluation of the Newcastle young adult service: What has been achieved?

Transition and young adult services should be evaluated to establish their effectiveness (Department of Health and Child Health and Maternity Services Branch, 2006). Evaluation measures used so far include satisfaction surveys and audit.

Feedback from discussion groups

Feedback from facilitated educational sessions has shown that participants valued the opportunity to share experiences (see Box 1).

Audit of outcomes after 3 years

The efficacy of our young adult clinic was

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Box 1. Feedback from the discussion groups.

"I found the group discussions useful because it is nice to talk to people who genuinely understand what I am going through. Also, sharing tips is quite useful."

"I thought the idea of the discussion group was excellent. It really allowed everyone to share their personal experiences to show not everyone has the same problems or symptoms. The informal setting was great as it encouraged everyone to put their opinions forward more openly. Overall, it was well done, especially for those who have not had diabetes for very long."

"I found it very useful. It was reassuring to hear others have similar experiences to me. I also gained advice on exercise."

determined with respect to glycaemic control, attendance rates and screening for complications. The database and case records were reviewed for all patients who had engaged with the clinic between 2004 and 2007.

Patient demographics

- Ninety-three young people attended the clinic during the review period; 51 (55%) were male.
- Two individuals have type 2 diabetes.
- The mean age of attendees was 21.2 years

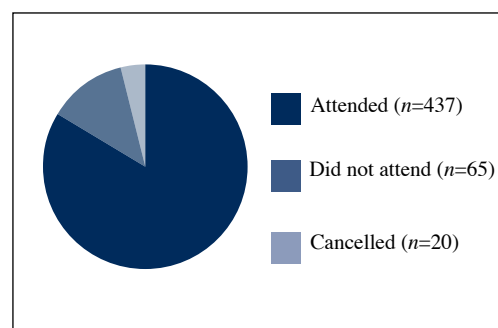


Figure 1. Attendance at the Newcastle young adult clinic (n=522).

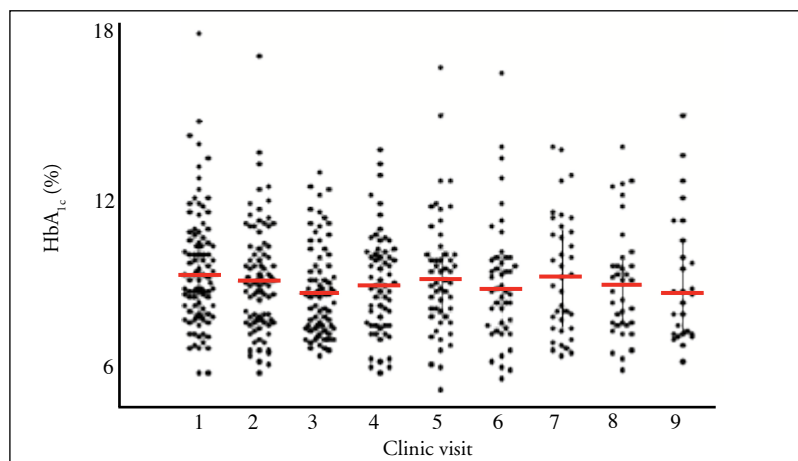


Figure 2. Individual HbA_{1c} values for the first clinic visit and subsequent visits. Each dot represents an individual HbA_{1c} value. The red bar shows the median HbA_{1c} for each clinic visit. Most individuals have not yet completed 3 years in the clinic, which explains the decrease in numbers at later visits.

HbA _{1c}	Visit 1 n=93	Visit 3 n=73	Visit 9 n=27
<7.5%	12 (13%)	17 (23%)	9 (33%)
<8.0%	21 (23%)	27 (37%)	10 (37%)

(range 18–24 years).

- The mean duration of diabetes was 10.8±0.5 years.

Attendance

A total of 522 clinic appointments were made over the study period, of which 84% were attended (Figure 1). This rate of attendance is achieved through effective communication by the DSNs between clinic appointments and the re-scheduling of cancelled appointments and ‘do not attends’. Along with helpline access to a DSN, this process ensures that the number of admissions to hospital with diabetic ketoacidosis remains extremely low. Newcastle had the lowest admission rate for this in a recent survey of the north-east region (<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937>).

Glycaemic control

The mean HbA_{1c} at first visit to the young adult clinic was 9.7% (range 6.0–18%; n=93). By their third visit, 8 months later, this had fallen to 9.0% (range 6.6–13.1%; n=73; P=0.008). Figure 2 shows the range and median HbA_{1c} for young adults from their first visit and over the next 3 years.

The proportion of young adults achieving an HbA_{1c} within the NICE (2004) target of <7.5% improved significantly (P=0.013). The number of individuals achieving the American Diabetes Association (2006) target of <8.0% also rose progressively from their transition into the clinic to their third visit and, in those who have been with us that long, to their ninth visit (Table 2).

Change in insulin regimens

At transition, 46% of young adults were taking twice-daily mixed insulin and 49% were on a basal-bolus insulin regimen, usually with insulin glargine and a short-acting analogue insulin. The young adult clinic has been a time of change in insulin regimen for many young people, with the proportion of those on a basal-bolus regimen rising to 74% after attending the clinic for 2 years (Table 3).

Uptake of screening for complications

Four young people moved away from the area.

Table 3. Change in proportion of young adults using basal–bolus insulin regimens as they progress through the young adult clinic.

	Visit 1 n = 93	Visit 3 n = 76	Visit 6 n = 46
BD	43 (46%)	23 (30%)	10 (22%)
Basal–bolus	46 (49%)	51 (67%)	34 (74%)
Pump	2 (2.2%)	1 (1.3%)	1 (2.2%)
Tablets	2 (2.2%)	1 (1.3%)	1 (2.2%)

BD = twice daily mixed insulin.

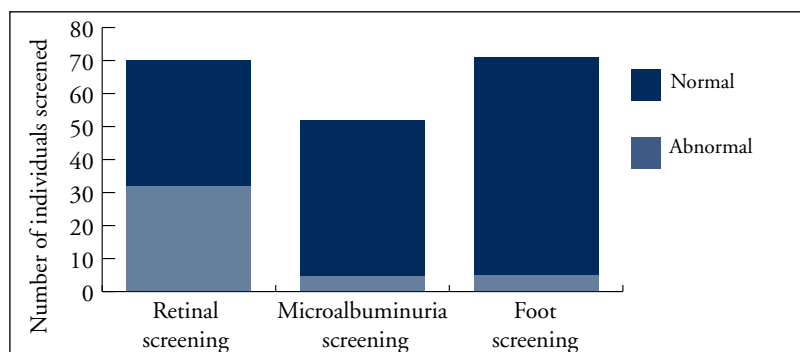


Figure 3. Screening for complications in the young adult clinic. The chart shows the number of patients screened for each complication and the number with an abnormal result, from a maximum of 89 patients. Abnormal results were any grade of retinopathy or an albumin:creatinine ratio $\geq 2.5\text{mg/mmol}$ for males and $\geq 3.5\text{mg/mmol}$ for females. Of the five people with abnormal foot surveillance, four had callus and one had suffered a traumatic fracture.

Of the remaining 89, 74 (83%) had attended for annual review in the previous 15 months. Screening for retinopathy was performed in 70 individuals; screening for foot complications was performed in 71 young adults; but only 52 were screened for microalbuminuria (Figure 3).

Conclusions

Although glycaemic control is suboptimal in the majority of young adults, the establishment of a young adult clinic has improved attendance and resulted in high rates of screening for complications in this high-risk population. Determination of microalbuminuria, requiring the young person to provide a urine sample, remains problematic. This is perhaps due in part to a lack of understanding of what screening will achieve, and partly also to the unacceptable issue of carrying a urine sample in their bag. This is an area that needs to be targeted.

Although the median HbA_{1c} and range of

HbA_{1c} levels do not appear to have improved consistently over the 3-year study period; there was a statistically significant reduction in the number achieving HbA_{1c} <7.5% between visits 1 and 3 ($P=0.013$). There was also considerable improvement in the number achieving a target of <8.0%, although this did not reach statistical significance. It is suggested that in those who are coping with their diabetes, the young adult clinic provides a stable environment for them to enhance their self-management skills and tighten their glycaemic control.

Further work is needed to establish the best approach to use with young adults who continue to have very poor glycaemic control despite intensive support from the multidisciplinary team. The high rates of psychology intervention demonstrate the importance of a non-threatening holistic approach to young adults. Research regarding the benefits of psychology screening for eating disorders and other psychological illness will be valuable.

Acknowledgements: We would like to thank all the young people who have come through the young adult service, and those currently attending the clinic, for their comments and contributions. In addition, our grateful thanks go to the wider multidisciplinary team.

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