

Transition of young people from paediatric to adult care

Position Statement (Updated: July 2018)

Why have we produced this position statement

Transition refers to the time when a young person moves from one diabetes service to another, typically from a paediatric service to an adult service, but it can also refer to moving between different adult services.

Diabetes can have a significant impact on a young person's life, and good management is vital to achieve positive health outcomes and a good quality of life. Regular contact with diabetes services is crucial to achieve this, but transition is a time when young people can fail to engage with services.

How did we develop this position?

We developed this position through knowledge gained from:

- Reviewing the relevant literature
- Reviewing data from the current National Paediatric Diabetes Audit⁽¹⁾ and National Diabetes Transition Audit⁽²⁾
- Reviewing current guidelines on transition
- Discussions with expert clinicians through Diabetes UK's Council of Healthcare Professionals and expert paediatric diabetes clinicians

We gained further insight by engaging with young people to find out their experiences of transition and their recommendations of what constitutes a good transition.

What we say about this issue

A transition service should have the young person at its centre, be responsive to their needs and be supported by expert healthcare professionals who are committed to working together to provide the care and support young people need.

The young person's transition should be a smooth process, so they can move through the process easily.

Recommendations

A transition service should:

- Have the young person at its heart
- Recognise that the young person is an individual with their own needs and wants
- Be flexible enough to meet the young person's needs
- Allow the young person to move through the transition process at their own pace, based on their confidence and maturity rather than their age

- Ensure that each young person has a well-planned transition.
- Offer appointments at times and places that work for young people
- Use social media, email, texts, apps or Skype to make it easier for them to contact clinic staff without missing work or education
- Ensure that timely and ongoing access to mental health services are integral to the service
- Link with any other health services that are looking after the young person, and this should include school or university when necessary
- Recognise that parents are undergoing their own transition as they come to terms with a change in the way they support their child. Transition services must be responsive to parent's needs, provide support and communicate with them appropriately

All staff involved in young person's care should:

- Give the young person a chance to build up a relationship with them and so build up their confidence with them
- Respect the young person, listen to them and not judge them
- Be as flexible as possible about how, where and when you see the young person
- Offer appropriate help if the young person is struggling with any emotional issues like eating disorders, depression, anxiety etc. This includes referral to specialist services where necessary
- Recognise that a young person has their own experience in looking after their diabetes and treating them as a partner in their own care
- Educate the young person about their diabetes so they understand how to look after it properly, and so helping them to build up their confidence to look after their diabetes themselves
- Give the young person clear information with a way and language they can understand
- Refer the young person to other health services at the right time should they need help with non-diabetes related assistance
- Start to prepare the young person for transition as early as possible, so it doesn't come as a sudden change
- Work with the young person to write their own individual plan for how their transition is going to work. It should be based on their own particular needs and build on their strengths and knowledge
- Make sure that there is one named person to support the young person through transition, and the young person knows how to contact them they need to

- Agree with the young person a target for their HbA1c, explain why they should try to meet this target and how they are going to help the young person to meet it
- Refer the young person on to the adult clinic when they are ready, and make sure that the move goes smoothly

Evidence and analysis

Evidence suggests that many young people do not get a good experience of transition and so do not have such good management of their diabetes.

Current situation

- In children and young people with Type 1 diabetes, HbA1c level rises as age progresses, with values being higher in females than males ⁽¹⁾
- The HbA1c target is more likely to be reached pre-transition compared to post-transition ⁽²⁾
- Young people are more likely to achieve targets for care processes related to complications before transition than they are after transition, in particular for blood pressure and cholesterol. This is irrespective of age at transition, gender, deprivation, ethnic group and those diagnosed in the few years prior to transition⁽²⁾
- The least variation in care process completion was seen when transition occurred between the ages of 16 and 19 years, reflecting that planned transition is most likely in this age group and therefore the impact on care process completion is more successfully managed. For young people moving to adult services before 16 years of age there is a decrease in care process completion post-transition, reflecting the fact that it is unlikely to have been a planned transition⁽²⁾
- The risk of retinopathy increases with age and is highest amongst adolescent females ⁽¹⁾
- The percentage of young people with Type 1 diabetes who have albuminuria increases with age ⁽¹⁾
- Annual measurement of HbA1c decreases after transition⁽²⁾
- Poor transition leads to recognisable impacts on health care resources through repeated non-attendance for planned care, increased use of urgent/out-of-hours care and increased complexity of need through secondary/avoidable complications⁽³⁾

References

- (1) National Paediatric Diabetes Audit (2018)
<https://www.hqip.org.uk/resource/national-paediatric-diabetes-audit-report-2016-17-care-processes-and-outcomes/#.W1crKfmPIY0>

- (2) National Diabetes Transition Audit 2003-2014 (2017)
https://files.digital.nhs.uk/pdf/g/m/report_v1.0.pdf
- (3) NHS England Diabetes Transition Service Specification (2016)
<https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf>