# Where are we now with transition?

very warm welcome back to our readers after what feels like a long hiatus. In an era of increasing market pressure and regulation, we appreciate the growing difficulties of providing funding for free, independent, peer-reviewed content. And so we begin this issue by extending our thanks to Lilly Diabetes for their continuing support, and to Dexcom and Abbott for their new support of this publication.

Looking ahead, we will be reducing the number of issues to two per year; however, we will be supplementing this with more frequent online content and newsletters, ensuring that readers are kept up to date with all the latest news and initiatives from the paediatric diabetes networks. Some of you will have already received our inaugural e-newsletter. For those healthcare professionals in the UK who have not, please email bookings@omniamed.com and ask to be added to the DCCYP mailing list.

# **Transition**

The word "transition", when used in the context of diabetes, means different things to young people, families, caregivers and healthcare professionals. However, all would agree that it has its challenges and, if not handled carefully, can result in young people not accessing the healthcare that they need. As a result, they can suffer from serious short-, medium- and long-term complications.

Transition is the process by which young people are prepared for the transfer to adult services. The move, which involves the young people taking a much more active role in their own health, takes place at a time when they are already facing all the usual trials and tribulations of teenage life. In the world of diabetes, the transition from childhood to adulthood is particularly sensitive to disruption. Sensitive collaborations are needed to engage the young person and provide appropriate medical, educational and psychological support, in order to ensure continuity of care and give young people the confidence to manage their diabetes.

Much has been written on this subject, and many meetings have been held to discuss the best ways of taking the transition agenda forward in diabetes care. We now realise that there is no "one-size-fits-all" approach when it comes to transition, as it is so important to personalise the healthcare plan for each individual. Young people do not really want to be told what to do, so we must find a way for them to do what we ask but think that it is their idea!

# The Diabetes Transition Service Specification

Recently, there has been a far greater national focus on improving transition services for young people with diabetes; however, many services are not doing this as well as they could. In an attempt to address unwarranted variation in clinical practice, NHS England (2016) published the *Diabetes Transition Service Specification*. This document was designed to support the development of optimal care pathways between paediatric and adult diabetes services for young people aged 12–24 years.

This specification is a non-mandatory service specification that commissioners may want to use to support effective transition. The specification is:

- In line with the national standard contract and allows for local adaptation and informed service design.
- In line with NICE guidelines for diabetes (type 1 and type 2) in children and young people and in adults.
- Supporting uptake of the National Diabetes Audit (NDA) and National Paediatric Diabetes Audit (NPDA), and completion of the nine care processes.

The specification provides guidance on how to support young people through an appropriate, personalised transition pathway into young adult services. Built on the common principles of concurrent life changes at this time, it also highlights a best practice service provision model that aims to identify the issues to be addressed in the development of any diabetesspecific transition service. It also acknowledges that many children and young people suffer more than one comorbidity or long-term condition, and so could be experiencing multiple service transitions simultaneously.

The specification sets out three stages for effective transition: planned preparation, movement and structured integration. It also lists six key considerations



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#### Box 1. Findings of the first National Diabetes Transition Audit report.

### Annual care processes

- Annual rates of HbA<sub>1c</sub> measurement decreases after transition.
- Annual measurement of blood pressure and cholesterol remains similar, whereas kidney, foot, retinopathy and smoking check completion rates increase after transition.
- The differences in care process completion pre- and post-transition do not appear to be influenced by gender, ethnicity, or living in a deprived area.
- Pre-transition annual care process completion rates fall as age at transition increases, while post-transition completion rates increase as age at transition increases. A similar pattern is seen for duration of diabetes.
- The least variation in care process completion rates was found where transition occurred between the age of 16 and 19 years. This may be because planned transition usually occurs during this time window. Planned movement from paediatric to adult care is less likely at younger and older ages.

#### Treatment targets - HbA<sub>1c</sub>

- The HbA<sub>1c</sub> target is more likely to be reached pre-transition compared with post-transition. The difference is greatest at younger ages.
- The decrease in meeting the HbA<sub>1c</sub> target is not influenced by gender, ethnicity, or living in a deprived area
  - N.B. For children living in the least deprived areas, there is still a difference in the achievement of the HbA<sub>1c</sub> target pre- and post-transition, emphasising the fact that transition is a very vulnerable time for everyone.

#### Treatment targets - risk factors

- For both cholesterol and blood pressure, the percentage of children achieving the targets is higher pre-transition compared to post-transition.
- This trend is irrespective of age at transition, gender and whether they live in a deprived area. The trend can be seen across different ethnic groups and for children diagnosed in the few years prior to transition.
  - N.B. Achievement of the pre-defined targets for blood pressure, cholesterol and kidney function is important for all people over the age of 12 years, as these are potential risk factors for complications in later life.

#### Diabetic ketoacidosis (DKA)

• There is a higher number of DKA admissions post-transition. However, this may be due to the fact that DKA rates increase with increasing duration of diabetes.

#### References

- NHS Digital (2017) National Diabetes Transition Audit, 2003–2014. NHS Digital, Leeds. Available at: www. digital.nhs.uk/catalogue/PUB30008 (accessed 26.09.17)
- NHS England (2015) National Children and Young People's Diabetes Peer Review Programme: Measures for children and young people's diabetes 2015. NHSE, London. Available at: https://is.gd/b2g9AC (accessed 26.09.17)
- NHS England (2016) *Diabetes Transition Service Specification*. NHSE, London. Available at: https://is.gd/ s1Q5rS (accessed 26.09.17)
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of effective diabetes transition services:

- 1. Accessible and engaging services/disengagement.
- 2. Partnerships and integration/coordinated services.
- **3.** Independence and autonomy.
- 4. Staged and timely.
- 5. Supportive structures and systems.
- 6. Integral psychological services.
- 7. Support for parent and carer transition.

The National Children and Young People's Diabetes Network has agreed to have transition as one of its priority work streams going forward and is encouraging diabetes teams across the country to use the Diabetes Transition Specification. As a result, the majority of paediatric diabetes units across England and Wales have engaged in service improvement models with their adult colleagues to streamline the transition care pathway and develop a transition policy. The need to have a policy in place is also embedded in the 2017–2019 Best Practice Tariff Specification (NHS Improvement, 2016) and in the Peer Review Programme measures (NHS England, 2015), which states that each unit must have a transition and transfer policy. There is also a requirement to engage young people in describing the experience of going through the transition process, in order to inform future service development.

# The National Diabetes Transition Audit

Outcome data on the transition phase has been sadly lacking to date, but in June 2017 the first National Diabetes Transition Audit (NDTA) report was published (NHS Digital, 2017). The audit reported on data collected between 2003 and 2014 across England and Wales.

This report has provided the first insight into outcomes of transitional services and has encouraged services to refocus on their models of care. It focuses on young people with type 1 diabetes (those with type 2 diabetes have not been reported on) and has established a cohort of 16 730 individuals. The NPDA and NDA datasets have been linked so that care can be tracked through transition to adult diabetes services. The first NDTA report presents the key findings and recommendations on care processes and treatment target achievement rates in age groups of 12–24 years. The key findings are summarised in *Box 1*.

These key findings help commissioners and services to focus their attention on areas that need improvement, and the report has made specific recommendations to foster a collaborative approach to improving outcomes in transition services.

## Conclusion

It is clear that there is a wealth of information and guidance available to assist diabetes teams to develop excellent holistic care for young people with diabetes. We must now take every opportunity to use all the resources that are available to improve the diabetes care that we offer to these very vulnerable individuals. Transition should be an agenda item to discuss at every diabetes Safety and Governance committee, in both children's and adults' services. The ultimate goal should be to develop a fully integrated service model for young people with diabetes aged between 12 and 24 years.

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