Paediatric and Adolescent Diabetes Transitional Care

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Key Documents Owner:	Dr West	Consultant Paediatrician
Approved by:	Paediatric Quality Improvement meeting	
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Key Amendments

Date	Amendment	Approved By
November 2018	Updated references and some minor changes in wording to reflect this. Changes in transitional ways of working in paediatric clinics such as age banded clinics and new updated transitional assessment/educational documentation to reflect current thinking and good practice	J West/Paediatric QI
19th Nov 2020	Document extended for 1 year	Dr J West/Paediatric QIM
26th March 2021	Document reviewed and approved for 3 years	Paediatric Guideline Review meeting
9th Feb 2024	Document reviewed and approved	Paediatric Guideline Review Meeting
1st December 2025	New transition pathway and admission information added	James West

INTRODUCTION

Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems. Adolescents are a unique age group who have needs which differ from both those of adults and children. For adolescents with diabetes, the intense management it requires can escalate the usual pressures on young people and their families to conform in relation to their social, physical and emotional development, thereby making the transition through adolescence far more difficult.

It is well documented nationally that a high number of young people with chronic health needs have increasing problems in adherence to treatment and can opt out of the care process in the first two years after transfer to the adult service. This can lead to increased risks in the likelihood of developing the short- and long-term complications associated with diabetes. By having a clear pathway that has timely appropriate education and informs the young person about the differences in adult care, the hope is that more young people will continue to engage with care providers and thereby improve their personal health outcomes. Young adulthood is the first time they have to become entirely responsible for managing their own care needs, very often outside the security of family life, and it is important to ensure they enter the adult service equipped with the right knowledge, information and support. They will also enter the adult service as a minority group for which there is no adolescent specialist practitioner. This highlights the need for supporting these young people to be able to engage well at appointments and understand the differences in the adult health care setting.

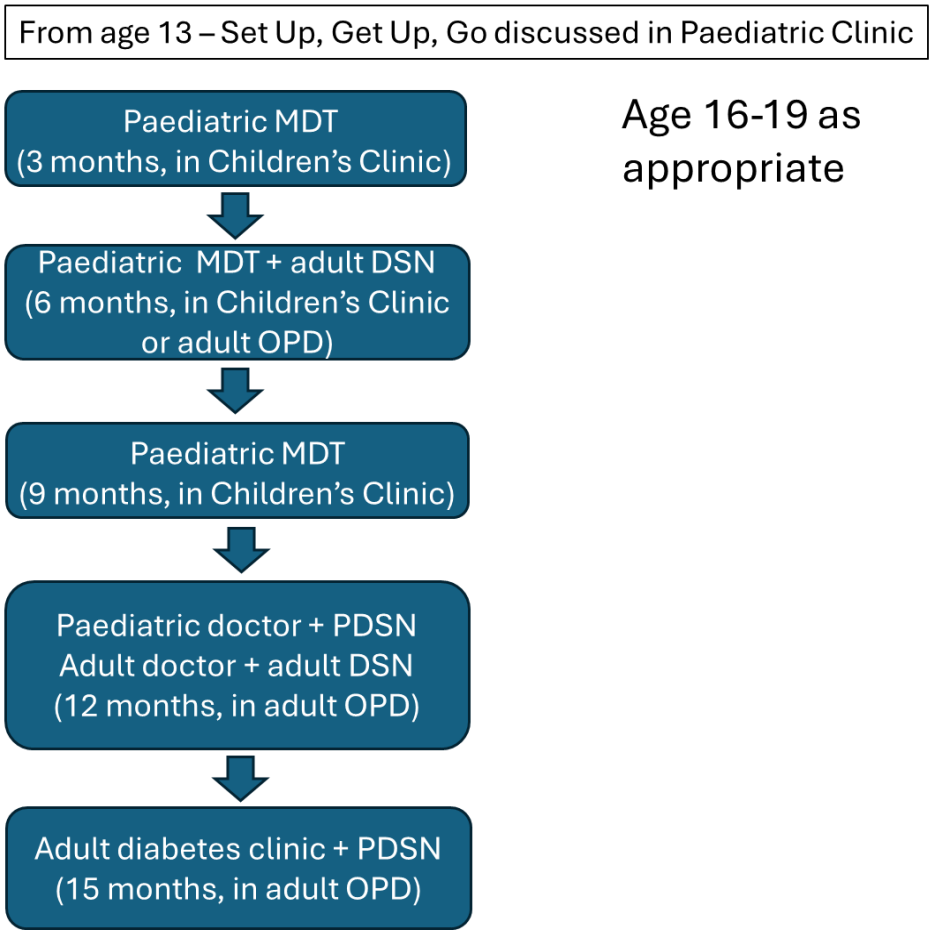
The National Service framework (NSF) for Children and Young people and for Diabetes, emphasises that the transitional process should be one that educates, guides and is an integral part of treatment and management plans. It is recommended good practice that transition planning should start in early adolescence and should not be seen as something which occurs just before transfer to the adult service.

DETAILS OF GUIDELINE

The transition process begins in the paediatric setting from 13 years of age onwards. Transition is discussed with the help of Set Up, Get Up, Go transition questionnaires. Set Up is aimed for 13–14-year-olds, Get Up for 15–16-year-olds and Go for 17–19-year-olds. However, this, as well as the rest of the transition process, should be flexible and individual to the young person's cognitive and physical development along with their emotional maturity, local circumstances and the individual's choice. **Vulnerable young people, such as those with learning difficulties/special needs, multiple problems or those in the looked after system may need a longer transitional period and additional resources on entering the adult service.** Equally there are those young people who may wish to move to the adult service before 18 years of age.

Completing Set Up, Get Up, Go will ensure that there is timely and ongoing education of relevant topics and encouragement to develop independent thought and consultation skills. Patients will gradually be encouraged to be seen in clinic independently whilst also allowing parents the opportunity to be involved. Each young person will be allocated a named key worker (it is likely this will be their Paediatric Diabetes Specialist Nurse) who will have responsibility for co-ordinating the process and collaborating with other multi-disciplinary and multiagency professionals where appropriate. At 18 years of age each patient will also have a named key worker within the adult diabetes service as transfer approaches (this is likely to be the Adult Diabetes Specialist Nurse who covers the geographical area where the young person lives). Both key workers need to ensure there are shared appointments around the time of transfer to help establish new professional relationships. Support should also be offered by either key worker when the young person attends their first adult Consultant appointment.

The process of transfer can occur between 16-19 years of age, (it more often happens when the young person is 18-19 years of age), via the following pathway.



In the final year with the paediatric service, the young person will still be offered four clinic appointments. Two of the young person's clinic appointments will be with the paediatric MDT (including a doctor, PDSN, diabetes dietitian +/- a clinical psychologist) in the paediatric clinic. The other two appointments include one appointment with the paediatric MDT and an adult DSN in either the paediatric or the adult clinic setting, and one appointment which includes the paediatric and adult doctors and nurses which is held in the adult clinic. At this final transition clinic appointment, the young person is asked to complete a feedback questionnaire on their transition experience to further improve our service.

After the last appointment with the paediatric team, the paediatric doctor will send a referral letter to the adult consultant to ensure ongoing care. If a young person DNA's any appointment during the transition process, the PDSN or adult DSN will contact the patient and further follow-up will be arranged. Patients are not discharged back to their GP's.

Each summer, the paediatric team will review how many patients are likely to be transferred to adult care over the following 12 months. This will allow sufficient time for the correct number of joint transition clinic to be set up on each site.

To minimise DNA's in the adult clinic, the young person's first clinic appointment solely with the adult team will be arranged for 3 months after the final joint transition clinic. Their paediatric diabetes specialist nurse will also try to attend this appointment with them to provide support.

Admission to hospital

All young people with diabetes under the age of 16 years will be admitted to Riverbank Children's Ward at Worcester Royal Hospital. Young people aged 16-19 years will be admitted depending on which hospital they present to:

Alexandra Hospital
Young people aged 16-18 years (up to 18th birthday) have a choice of being admitted to Riverbank Children's Ward at Worcester Royal Hospital or an adult ward at the Alexandra Hospital. Young people aged 18-19 years still under the paediatric diabetes service, will be admitted to an adult ward at the Alexandra Hospital. Medical responsibility for managing patients admitted to the Alexandra Hospital will lie with the adult medical team, although members of the paediatric diabetes team will try to review the patient if they're admitted during normal working hours (Monday-Friday, 9am-5pm).

Worcester Royal Hospital
Young people under 17 years of age will be admitted to Riverbank Children's Ward. Young people aged 17-18 years (up to 18th birthday) have a choice of being admitted to Riverbank Children's Ward or an adult ward at Worcester Royal Hospital. Young people aged 18-19 years will be admitted to an adult ward. Medical responsibility for managing patients admitted to an adult ward at Worcester Royal Hospital will lie with the adult medical team, although members of the paediatric diabetes team will try to review the patient if they're admitted during normal working hours (Monday-Friday, 9am-5pm).

Patient information

With a view to encouraging the young person to self-manage, there is clear, timely written information available for the young person about relevant educational topics and locality based adult service information. The young person will also be encouraged to keep copies of their clinic letters to be able to track and understand their investigations, results and targets.

The following leaflet 'Transition to Adult Diabetes Service: What's it all about?' is handed out to young people in the year before transition.

Transition to Adult Diabetes Service.doc

The following patient/parent information leaflets are also available:

- Young Person's Information: Emotional Wellbeing Support in Adulthood
- Young Person's Information: Negotiating independence
- Parent Information: Encouraging independence in your son or daughter
- Parent Information: Transition to adult diabetes service: what's it all about?

University

Moving away to go to university can be a time when young people get lost in the system. Many choose to continue their diabetes healthcare from their home address and appointments will be timed to coincide with university holidays.

The West Midlands Paediatric Diabetes Network has produced an up-to-date list of Adult Diabetes Service providers in the region. The paediatric team will also be able to advise on this.

Vulnerable young adults

Individualised transition and transfer arrangements may be agreed for patients with additional or complex needs. Young people who are vulnerable are highlighted as such on transfer to the adult service. Vulnerable young people include those in the looked after or after care system (they can be in this system up until the age of 25 years) and those with complex health/disability needs or learning difficulties and may require a multi-agency approach.

The adult service take additional care to try and maintain contact with a young person who transfers to their service as vulnerable. This is done by the new key worker making contact and offering further reviews during their first year in the system.

REFERENCES

NHSE Diabetes Transition Service Specification, January 2016

Monitoring and Compliance

This section should identify how the Trusts plan to monitor compliance with and the effectiveness of this Treatment pathway. It should include auditable standards and/or key performance indicators (KPIs) and details on the methods for monitoring compliance.

WHAT?	**HOW?**	**WHO?**	**WHERE?**	**WHEN?**
These are the 'key' parts of the process that we are relying on to manage risk.	***What are we going to do to make sure the key parts of the process we have identified are being followed?***	***Who is responsible for the check?***	***Who will receive the monitoring results?***	***Set achievable frequencies.***
The management of type 1 diabetes in children and young people	Submit data to the National Paediatric Diabetes Audit	Dr James West and Dr Corinne Hield	The Paediatric Diabetes Multidisciplinary Team, the Paediatric Directorate and the ICB.	Annually
The management of diabetic ketoacidosis in children and young people	Submit data to the West Midlands Paediatric Diabetes Network DKA audit when requested. If not regularly requested a local audit will be performed.	Dr James West and Dr Corinne Hield	The Paediatric Diabetes Multidisciplinary Team, the Paediatric Directorate and the ICB.	Annually
Paediatric & adolescent diabetes transitional care	Submit data to regional and national transition audits when requested. To obtain local data on an annual basis.	Dr James West and Dr Corinne Hield	The Paediatric Diabetes Multidisciplinary Team, the Paediatric Directorate and the ICB.	Every 2 years