Paediatric and Adolescent Diabetes Transitional Care

Key Document code:	WAHT-TP- 045	
Key Documents Owner:	Dr West	Consultant Paediatrician
Approved by:	Paediatric Quality Improvement meeting	
Date of Approval:	9th February 2024	
Date of review: **This is the most current version and should be used until a revised document is in place**	9th February 2027	

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

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" (Blum et al 1993). Adolescents are a unique age group who have needs which differ from both those of adults and children (Skinner 2000, Carson 2003, RCN 2004). 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 (Christie et al 2003 RCPCH 2003).

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 (Bradbury & Jenkinson 1996, Kipps et al 2002, RCN 2008). 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 (Dovey-Pearce 2005). 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 (Forbes et al 2001). 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 (2004) and for Diabetes (2003), highlight 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 will begin in the paediatric setting with early transition identified at the age of 13 years. The young person should be supported to transfer to the adult service at approximately 18 years. However, this should be flexible and individual to the young person's cognitive and physical development along with their emotional maturity, local circumstances and 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.

From 13 years of age patients will be seen in the Transition clinic. The transition document 'Goals of Diabetes' (please see M:\Acute\Diabetes\DiabetesCountywide\Paediatric team\Goals of Diabetes\new GOD 2017) will be held in the young person's nursing notes and brought to the clinic setting for completion by any Paediatric Diabetes Team member as appropriate. It will be a record of their transition, development and education. Completing the documentation will ensure that there is timely 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 17 years of age each patient will also have a named key worker within the adult diabetes service as transfer approaches (again this is likely to be an Adult Diabetes Specialist Nurse). 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.

With a view to encouraging the adolescent to self-manage, there should also be clear, timely written information available for the young person about relevant educational topics, locality based adult service information (see pages 7-15 for locality based patient information leaflet for each site) and the differences in targets to be achieved. They will also be encouraged to keep copies of their clinic letters to be able to track and understand their investigations, results and targets.

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. It is important to ensure the young person knows they can ring the appropriate secretary if they need to ensure an appointment is timed for the holiday period when they are home.

The West Midlands Paediatric Diabetes Network have produced an up to date list of Adult Diabetes service providers in the region. The paediatric team will 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 need to be highlighted as such on transfer to the adult service. Vulnerable young people will 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.

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

See flow chart on next page to clarify the Transitional Care Pathway.

TRANSITIONAL CARE PATHWAY

Vulnerable young person requiring adult service ongoing care for diabetes

Young person requiring adult ongoing care for diabetes

Age 13 years

Move to Transition clinic.
Allocate key worker from the multidisciplinary paediatric diabetes team.
Liaise with multiagency team if required.
Commence Transitional pathway document to be kept in nursing notes and brought to clinic to review.

Age 13-18 years

Review at MDT transitional diabetes clinic every 3 months.
Complete Goals of Diabetes documentation.
Additional contacts in between clinic appointments as necessary.

Vulnerable young person
Age 17-19 years

Consider more flexible/later transfer if appropriate.
Multi-agency approach if individual needs dictate.
Allocate adult diabetes service key worker.
Arrange joint key worker appointment(s).
Give written information on local Adult diabetes service.

Age 17-18 years

Allocate adult diabetes service key worker.
Arrange joint key worker appointment(s).
Give written information on local

Transfer to Adult service

Consultant to Consultant referral letter to adult service.

PDSN to DSN key worker letter or handover of the transition pathway document to new key worker.

Offer support from either paediatric or adult key worker at first adult Consultant appointment.

Adult Diabetes Team Service

Adult service key worker to maintain regular contact with young adult for at least a year. This is to help establish a good professional relationship.
May require extra individual contacts if vulnerable and multiagency working.
If two DNA appointments at Consultant clinic, Consultant to write to young person and automatically refer to DSN service to try to maintain contact.

Worcestershire NHS
Acute Hospitals NHS Trust

Paediatric and Adolescent Transition Pathway
Patient Document

Interdisciplinary transition planning check list
record including Goals of Diabetes

Patient Name.....DOB.....

Address.....

.....Post Code.....

NHS Number.....Unit Number.....

Type of Diabetes.....

Other conditions/problems? .....

Consultant Paediatrician.....

Named Key worker (Paediatrics).....

Named key worker (Adult).....

Dietician.....

GP.....

Education (SENCO or other if needed).....

Psychology support.....

Social worker.....

Other .....

Adult Consultant Diabetologist.....

Is this young person a vulnerable adult? Yes/ No

If yes give details.....

.....

Transition start date..... Finish Date…….....

Transfer to adult service preparation/ appointments

- Joint appointments with Paediatric and Adult service key worker:

  Date..... Adult Key worker.....

  Date.....

  Date.....

- Adult service Consultant appointment Date.....
  Consultant Name.....

- Support at Consultant appointment from key worker required? Yes/No

Has written information been given on key relevant young adult topics?

- ☐ A4 information folder to keep information/ appointments
- ☐ Street Drugs and smoking
- ☐ Alcohol
- ☐ Exams
- ☐ Driving
- ☐ Body Piercing and Tattoos
- ☐ Pre pregnancy planning
- ☐ Leaving Home
- ☐ Localised Moving up to the Adult service information and targets leaflet given.
- ☐ Informed of My Life section for young adults – Diabetes UK Web site

☐ Any outstanding education from Goals of diabetes/Transitional document?

……

……

- Consultant handover letter done - Date.....
- Key worker handover &/or letter done - Date.....
- **Formal handover to Adult service key worker and transition process complete**

Name & Signature: .....Date.....

Appendix 2 Localised Patient Adult Service Leaflets

Diabetes

Worcestershire Diabetes Service – moving up to the adult service

Your local Wyre Forest Diabetes Team based at Kidderminster Hospital consists of:

Position waiting recruitment	Consultant Endocrinologist
Jadwiga Borns	Diabetes Specialist Nurse
Sarah Almond	Diabetes Specialist Nurse
Sarah Raine	Diabetes Specialist Nurse

Your keyworker is.....

Other Services

Tracey Jones /Lee-Ann Edwards	Paediatric Diabetes Specialist Nurse
Dorota Amador Bueno	Dietitian Kidderminster Hospital

Clinics are held as below:

Dr ……

- Friday PM Kidderminster Treatment Centre – Young person's clinic first Friday each month
- Tuesday PM Kidderminster Treatment Centre (pregnancy/insulin pump patients)

Some consultant clinics will have other doctors working in them called registrars, so you may not see your consultant every time. From time to time medical students may also be observers in clinic as part of their learning.

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Contacting Dr …….

He is based at both Worcester Royal Hospital and Kidderminster Hospital.

Contacting the Diabetes Specialist Nurses:

Diabetes Specialist Nurses for adult services are based at:

The Fred Holland Centre for Diabetes
C Block 3rd floor,
Kidderminster Hospital
Bewdley Road
Kidderminster
Worcs
DY11 6RJ

Their contact numbers:

Sarah Almond - part time 01562 512324 – 24 hr answer-phone

Jadwiga Borns - full time 01562 826385 – 24 hr answer-phone

Sarah Raine - part time 01562 512322 – 24 hr answer-phone

The Diabetes Nursing team operates a Monday to Friday service, with no service on Bank Holidays. Nurse- led clinics are held at the Diabetes Centre at Kidderminster hospital. You may also see them working in partnership with your GP practice and in the consultant clinic. You can contact the nurses direct for advice regarding your diabetes on the numbers given above. If you wish to book an appointment, please leave a message on the answer phone for them to contact you.

It is important to realise that you will no longer be able to have home visits as you have done in the paediatric service and it is very much your responsibility to make contact when you require advice or support now you are an adult.

Contacting Dieticians

You will need a referral to this service from your Consultant, Diabetes Nurse or your GP or Practice Nurse. As well as one to one advice the dietetic service also provides courses to help you improve your own self management of diabetes.

Contacting to change your appointments

Should you have any query regarding your hospital appointment contact the number on your appointment letter or card. Having your hospital number to hand will help speed up any query you have.

If your appointment is with the Diabetes Specialist Nurses at Kidderminster then contact them direct.

Where to seek advice

Your first line of advice about diabetes during a normal working day should be the Diabetes Specialist Nurses or your GP practice.

For out of hours advice (after 5.00pm and before 08.30am), weekend and Bank Holiday advice, please contact the 111 service.

Getting the most out of your appointment

Bring along your diary or computer download of your blood glucose meter results to discuss patterns and trends with your health professional. Think about questions you would like to ask beforehand to get the most out of your consultation. Ask if there is anything you do not understand about any of your treatment or the investigations that may be suggested. This is your appointment so make the most of it.

Know your Numbers

There has been lots of research that tells us that to keep yourself in the best of health with diabetes, you should aim to keep the following tests within the range given below:

- **Blood Glucose Levels 4-7mmol/l pre meals and up to 9 mmol/l 2 hours after meals (You should be 5mmol/l or above before driving and pre bed target 5-8mmol/l).**

- **HbA1c 48mmol/l**
- **Blood Pressure 130/80 or less.**
- **Cholesterol 4mmol/l or less**

These may seem difficult to achieve for some and you should discuss personal targets with your health professional.

Other Support

- There is **a Diabetes UK Kidderminster Branch**/Self Help group. Contact Fred Holland 01562 68649 for more details.
- Diabetes UK have an excellent part of their web site for young adults called ”My Life” at www.diabetes.org.uk
- www.jdrf.org.uk is another good web site to access
- If you are very keen on sport then www.runsweet.com is an excellent site giving practical advice and knowledge on how to manage your particular sport.
- If you require support with your mental health you can talk to your GP, diabetes consultant and/or nurse about the struggles you are experiencing, as they will know which service(s) can best support your needs. For Worcestershire, you can also contact the Worcestershire Wellbeing Hub on 01905 766124 or WHCNHS.wellbeinghub@nhs.net for advice.

Diabetes

Worcestershire NHS

Worcestershire Diabetes Service – moving up to the adult service

Your local Redditch & Bromsgrove Diabetes Team consists of:

Alexandra Hospital

Dr Irfan Babar	Consultant Endocrinologist
Dr Abdul Safi	Consultant Endocrinologist

NatalieTrigg, Wendy Butters, Sara Molineaux
Diabetes Specialist Nurses, Alexandra Hospital Site

Community Diabetes Specialist Nurses – Adult Service

Jane Wilson
Hannah Webb
Suzy Reynolds
Sarah Molineaux

Your new key worker is.....

Other Services

Becki Walling	Paediatric Diabetes Specialist Nurse
Dietitian Service	Alexandra Hospital

Clinics are held as below:

Dr Babar

- Tuesday Mornings Alexandra Hospital Redditch
- Thursday Afternoons Princess of Wales Hospital Bromsgrove

Dr Safi

- Wednesday morning Princess of Wales Hospital Bromsgrove

All Consultant clinics will have other Doctors working in them called Registrars so you may not see your Consultant every time. From time to time medical students may also be observers in clinic as part of their learning.

Contacting Dr Babar and Dr Safi

They are based at:
The Alexandra Hospital
Woodrow Drive
Redditch, Worcs
B98 7UB

Ring the Hospital number **01527 503030** and ask for Dr Babar's secretary. If you are at University they will help you accommodate requests for home time appointments rather than ringing through to the Outpatient service.

Contacting the Community Diabetes Nurses:

Both the Paediatric Nurse and the Community Diabetes Specialist Nurses for adult services are all based at:
The Diabetes Centre
Smallwood House
Church Green West
Redditch, Worcs
B97 4BD
Community Diabetes Nurses for adult services

Answer phone & Fax Tel 01527 488649

The Diabetes Nurses operate a Monday to Friday service, with no service on Bank Holidays. Currently Jane Wilson & Suzy Reynolds run nurse led clinics at the Princes of Wales Hospital and Hannah Webb and Suzy Reynolds run nurse led clinics at the Diabetes Centre Smallwood House. You may also see them working in partnership with your GP practice. You can contact the nurses direct for advice on your diabetes by phone or for an appointment. Leave a message on the answer phone for them to contact you.

It is important to realise that you will no longer be able to have home visits as you have done in the paediatric service and it is very much your responsibility to make contact when you require advice or support now you are an adult.

Contacting the Hospital Diabetes Nurse:

This will be mainly for those of you who are young adults that are an inpatient, those who are pregnant and also for discharge from hospital follow up. The nurse will give you her direct details when required.

Contacting Dietitians

You will need a referral to this service from your Consultant, Diabetes Nurse or your GP or Practice Nurse. As well as one to one advice the dietetic service also provides courses to help you improve your own self management of diabetes.

Contacting to change your appointments

Should you have any query regarding your hospital appointment contact the number on your appointment letter or appointment card. Having your hospital number to hand will help speed up any query you have.

If your appointment is with the Community diabetes nurses at Smallwood House or the Princess of Wales then contact them direct.

Where to seek advice

Your first line of advice about diabetes during a normal working day should be the Diabetes Nurses or your GP practice.

For out of hours advice (after 5pm and before 08.30am), weekend and Bank Holiday advice, please contact the 111 service.

Getting the most out of your appointment

Bring along your diary or computer download of you blood glucose meter results to discuss patterns and trends with your health professional. Think about questions you would like to ask beforehand to get the most out of your consultation. Ask if there is anything you do not understand about any of your treatment or the investigations that may be suggested. This is your appointment so make the most of it.

At each Consultant appointment you have you will be given a form for a standard blood test to have a week before your next appointment. This is so that you Consultant can discuss your HbA1c result with you when you see them. You will also be asked to give a fresh urine sample to the clinic nurse, you can bring this with you or use the toilet in the outpatients area.

Know your Numbers

There has been lots of research that tells us that to keep yourself in the best of health with diabetes, you should aim to keep the following tests within the range given below.

- **Blood Glucose Levels 4-7mmol/l pre meals and up to 9mmol/l 2 hours after meals (you should be 5mmol/l or above before driving and pre bed target 5-8mmol/l).**
- **HbA1c 48 mmol/mol or less**
- **Blood Pressure 130/80 or less.**
- **Cholesterol 4mmol/l or less**

These may seem difficult to achieve for some and you should discuss personal targets with your health professional.

Other Support

- Diabetes UK have an excellent part of their web site for young adults called ”My Life” at www.diabetes.org.uk
- www.jdrf.org.uk is another good web site to access
- If you are very keen on sport then www.runsweet.com is an excellent site giving practical advice and knowledge on how to manage your particular sport.
- If you require support with your mental health you can talk to your GP, diabetes consultant and/or nurse about the struggles you are experiencing, as they will know which service(s) can best support your needs. For Worcestershire, you can also contact the Worcestershire Wellbeing Hub on 01905 766124 or WHCNHS.wellbeinghub@nhs.net for advice.

Worcestershire NHS

Diabetes

Worcestershire Diabetes Service – moving up to the adult service

Your local Worcester Diabetes Team consists of:

Worcestershire Royal Hospital

Dr M Allam **Consultant Endocrinologist**

Marie Major and Caroline Rolfe Diabetes Specialist Nurses, Worcester Hospital Site

Community Diabetes Specialist Nurses – Adult Service

Alison Hall
Susan Rogers
Lisa Smith
Rebecca Choyce

Your Key worker is:.....

Other Services

Esther Anstey / Jane Francis Paediatric Diabetes Specialist Nurses
Dietitian Service Worcestershire Royal Hospital

Consultant clinics are held as below:

Dr Allam

- On variable days in the Diabetes Centre

All Consultant clinics will have other Doctors working in them called Registrars so you may not see your Consultant every time. From time to time medical students may also be observers in clinic as part of their learning.

Nurse led Clinics

These are usually held every first Tuesday of the month at the Diabetes Centre, Worcester.

Contacting Dr Allam

They are based at:
The Diabetes and Endocrinology Centre
Aconbury East
Worcester Royal Hospital
Charles Hastings Way
Worcester
WR5 1DD

Ring the Diabetes Centre number **01905 760726** should you have any query.

Contacting the Community Diabetes Nurses:

Both the Paediatric Nurse and the Community Diabetes Specialist Nurses for adult services are all based at:
The Diabetes and Endocrinology Centre
Aconbury East
Worcester Royal Hospital
Charles Hastings Way
Worcester
WR5 1DD

Community Diabetes Nurses for adult services

Answer phone Tel 01905 733834

The Diabetes Nurses operate a Monday to Friday service, with no service on Bank Holidays. You may also see them working in partnership with your GP practice. You can contact the nurses direct for advice on your diabetes by phone or for an appointment. Leave a message on the answer phone for them to contact you.

It is important to realise that you will no longer be able to have home visits as you have done in the paediatric service and it is very much your responsibility to make contact when you require advice or support now you are an adult.

Contacting the Hospital Diabetes Nurse:

This will be mainly for insulin pump patients, those who are pregnant and for discharge from hospital follow up. The nurse will give you her direct details when required.

Contacting the Dietitian

You will need a referral to this service from your Consultant, Diabetes Nurse or your GP or Practice Nurse. As well as one to one advice the dietetic service also provides courses to help you improve your own self-management of diabetes.

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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	The paediatric multidisciplinary diabetes team and the paediatric department. The CCG's.	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 Naeem Ahmad	The paediatric multidisciplinary diabetes team and the paediatric department.	Annually
Paediatric & adolescent diabetes transitional care	Submit data to the West Midlands Paediatric Diabetes Network transition audit when requested. If not regularly requested a local audit will be performed.	Dr James West	The paediatric multidisciplinary diabetes team and the paediatric department.	Every 2 years

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