

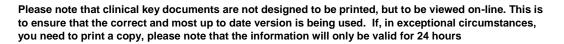
# Operational Policy for the Children and Young People with Diabetes Multidisciplinary Team (MDT)

# **Worcestershire Acute Hospitals NHS Trust**

# **Revised May 2024**

This operational policy was agreed by the Worcestershire Paediatric Diabetes Team on  $2^{\text{nd}}$  May 2024

Approved by – Paediatric Quality Improvement Meeting – 15<sup>th</sup> May 2024 Date for review: 15<sup>th</sup> May 2027





# **Contents**

Introduction	
Responsibility and Duties	3
Aims and Objectives of the CYPD Team	4
Philosophy of Care	4
Trust Wide Management Group (H1)	5
Twenty-Four Hour Advice Service (H2)	
Device Download Facilities (H3)	
Point of Care Testing for HbA1c (H4)	
Riverbank Children's Ward Training (H5)	
Outpatients' Consultation Time (H6)	
CYPD MDT Measures	
Leadership arrangements and responsibilities (M1)	
Core Membership (M1)	
Ongoing Specialist Training (M1)	
Clinical Guidelines (M3)	
Patient Pathways (M4)	
Primary Care Communication (M5)	17
Patient Choice of Insulin Pump Therapy (M6)	
Continuous Glucose Monitoring (CGM) (M7)	
Hybrid Closed Loop Systems	
Multidisciplinary Follow-Up Appointments (M8)	
HbA1C Measurement (M9)	
Dietetic Assessment (M10)	
Psychological Assessment (M11)	
Additional Contacts (M12)	
Did Not Attend Policy (M13)	
Support for Children in Education (M14)	
Screening of Children and Young People with Diabetes (M15)	24
Transition and Transfer Policy (M16)	20
Key Worker (M18)	
Patient Information and Support (M19)	
Individualised Objectives (M20)	
Diabetes Self-Management Education (M21)	
Record of Care (M22)	
Miscellaneous	
Implementation	
Monitoring and compliance	
References	
Supporting Documents	
Appendices	
Appendix 1 – Mission statement	
Appendix 2 - Paediatric Diabetes Countywide Meeting	39
Appendix 3 - West Midlands Paediatric Diabetes Network agreed 24-hour advice service	4.4
specifications	
Appendix 4: Out-of-hours Advice Leaflet	
Appendix 5 - Patient Pathways	
Appendix 6 – GP letter templates	
Appendix 7 - Paediatric Diabetes Multidisciplinary Team (MDT) Home Visit Guideline	54



### Introduction

The purpose of this document is to provide a comprehensive written guide of services offered to children and young people (CYP) with diabetes in Worcestershire. It also intends to clarify individual roles and responsibilities within the team and combines existing service delivery guidelines.

The service currently provides care to approximately 315 CYP up to 19 years of age within Worcestershire but also includes a small number of Warwickshire and other out of area CYP. The Paediatric Diabetes multidisciplinary team is spread across the County in the 3 localities of Redditch and Bromsgrove, Worcester and the Wyre Forest providing a local service in each area. It should be noted that Worcestershire is a mostly rural County and this needs to be taken into consideration in delivering the service.

Multi-disciplinary clinics take place at Worcester Royal Hospital, The Alexandra Hospital (Redditch) and Kidderminster Hospital sites. The Paediatric Diabetes Specialist Nurses provide a home visiting and school support service together with ongoing support by telephone, email, in clinic and other settings as appropriate. Dietitians offer telephone support and have their own clinics set up on each site where they see patients for additional appointments. There is also a need for the dietitians to conduct some home visits for difficult to reach or vulnerable families. Clinical psychology support is available at many clinics and some 1:1 patient or family work takes place at separate speciality appointments outside the consultant-led MDT clinic often at the hospital bases but sometimes at home or school. All admissions are to Riverbank (children's) Ward at Worcestershire Royal Hospital.

### Scope of this document

This policy describes a current overview of the Paediatric Diabetes Service.

### **Definitions**

CYP Children and young people

PDSN Paediatric Diabetes Specialist Nurse

MDT Multidisciplinary team

HbA1c Glycated haemoglobin (a marker of average blood glucose levels over the last 2-3

months)

CGM Continuous glucose monitoring

FGM Flash glucose monitoring

NICE The National Institute for Health and Care Excellence

DKA Diabetic ketoacidosis

Hypo Hypoglycaemia (defined as a blood glucose level <4mmol/l in a type 1 diabetic)

DNA/WNB Did not attend/Was not brought EQA External quality assessment SOP Standard operating procedure

# **Responsibility and Duties**

This operational policy lays out the core principles and delivery of the service for the key members of the diabetes MDT. It also includes service delivery for medical/nursing staff that come into contact with



CYP with diabetes for out-of-hours advice, inpatient management and the community nurses (Orchard Service).

### Aims and Objectives of the CYPD Team

To provide consistent, high-quality care to CYP with diabetes, their families and care providers. We hope to achieve this by:

- Making the care of CYP and their carers our main priority
- Reducing CYP's HbA1c across the whole county
- Providing a comprehensive structured education programme
- Performing and documenting all required care processes at the time of annual review
- Providing insulin pump therapy, CGM's and/or hybrid closed loop systems to CYP that satisfy NICE criteria
- Providing an effective transition service
- Having an active quality improvement programme
- Ensuring that policies, protocols and procedures for the hospital are up to date
- Satisfying the paediatric diabetes Best Practice Tariff criteria
- Submitting data to the National Paediatric Diabetes Audit
- Listening to PREM feedback and improving the quality of service provided
- Providing a range of social events for our CYP and their carers

### Philosophy of Care

We will offer care, support and education to CYP and their carers to optimise quality of life and to enable the CYP to become independent in managing their own diabetes competently and safely by the time they reach adulthood by:

- Offering at least 4 HbA1c checks and 4 clinic appointments per year with a paediatric diabetes doctor, nurse and dietitian
- Offering annual screening for complications including blood tests for thyroid function and coeliac screen for all ages and a cholesterol blood test, foot examination, urine for microalbuminuria and retinopathy screen (biannually) for over 12-year olds
- Offering psychological screening at least annually, and assessment and psychological support to CYP and their carers from team clinical psychologists as well as other MDT members, as required
- Being available for extra support, advice, troubleshooting and check-ups by e-mail, telephone and at follow-up appointments
- Offering home visits when required
- Offering an additional appointment with a dietitian once per year and as required
- Offering ongoing education tailored to the needs of the CYP and their care providers including structured education events, teaching in schools, at home visits and in clinics. Some of this will be included in social activities for the CYP and their carers
- Supporting the young person through transition and transfer to adult diabetes services

A mission statement of the service is displayed in each clinic (see Appendix 1).



# **Policy detail**

# Trust Wide Management Group (H1)

The Trust wide management group responsible for the co-ordination and care of CYP with diabetes is the Worcestershire Paediatric Diabetes Team at Worcestershire Acute Hospitals NHS Trust led by Dr James West and Dr Corinne Hield (Consultant Paediatricians and Clinical Leads for Paediatric Diabetes).

The membership of this group includes:

Role	Team Member
Women's & Children's Directorate Manager	Michael Croutear
Lead Paediatric Consultants for CYPD	Dr James West and Dr Corinne Hield
Lead Paediatric Specialist Nurse for CYPD	Becki Walling
Lead Paediatric Specialist Dietitian for CYPD	Dorota Amador Bueno
Lead Clinical Psychologist for CYPD	Dr Amy Symonds
Lead Consultant for care of adults with	Dr Irfan Babar
diabetes	
Trust Lead for point of care testing	Adedoja Adeseye
Head of Children and Young People's	Amrat Mahal
Nursing	
Matron for Children's services	Dana Picken

The accountability of this group is to the Paediatric Quality Improvement Group. Countywide meetings are held every 2 months and all members of the Trust wide management group and CYP's diabetes team are invited. Other members are co-opted to attend when relevant. Minutes are documented electronically for governance purposes and action plans are discussed at the Children's Quality Improvement (governance) meeting. The Quality Improvement Group is accountable to the Women and Children's Directorate which in turn is accountable to the Trust Board.



Fig 1: Governance structure overseeing the Paediatric Diabetes Service



Significant risks are added to the risk register and are discussed at both the Quality Improvement and the Women and Children's Divisional meetings. Clinical incidents (Datix's) are investigated and discussed at the Countywide meetings. Newly diagnosed CYP are discussed as well as those CYP admitted with DKA, hypo's and for restabilisation; DNA/WNB rates are reviewed according to age bands. In addition to these countywide meetings, twice a year there is a diabetes MDT away day or half day to discuss quality improvement strategies.

Terms of Reference are in Appendix 2.

### **Twenty-Four Hour Advice Service (H2)**

The CYP's West Midlands Paediatric Diabetes Network has agreed the specifications for a 24-hour advice service, seven days a week (Appendix 3):

- 1) for telephone advice on diabetes management to patients/carers
- 2) for telephone advice to health care professionals (HCPs) on the management of CYP with diabetes admitted to hospital
- 3) for the local team's escalation policy to the tertiary centre at Birmingham Children's Hospital

### 1) Telephone advice on diabetes management to patients/carers

CYP and their carers can contact the PDSN's during normal working hours (9-5pm) Monday to Friday. All CYP and families have written information on the locality service and contact telephone numbers. There are many days when the PDSN's provide a later service to accommodate after school visits and group structured education and therefore are available for later calls. For out-of-hours support, there is a clear communication pathway for CYP to contact Riverbank Children's Ward, which has up-to-date guidelines to ensure appropriate, consistent advice for urgent and long-term insulin adjustment.

Guidelines to refer to:

- WAHT-PAE-039: Paediatric Diabetes Sick Day Management/hyperglycaemia and Ketosis in the Community
- WAHT-PAE-038: Nursing Protocol for Insulin Adjustment in the Community

### Open access for patients to Riverbank Ward and advice from HCPs

All CYP have open access to Riverbank Ward for when emergency issues (potential or actual) arise after prior assessment by telephone call.

#### 2) Telephone advice to HCPs on the management of CYP with diabetes admitted to hospital

If the on call Paediatric middle grade requires advice or support, they should contact the on call non-diabetes specialist Paediatric Consultant. If further help is needed the on call non-diabetes specialist Paediatric Consultant can contact either Dr West or Dr Corinne Hield (Consultant Paediatrician and clinical lead for paediatric diabetes).

Advice line and contact sheets are in Appendix 4.

#### 3) Escalation policy for healthcare professions to gain additional advice 24/7

For more complex cases or management of severe DKA, advice can be sought from the Regional Endocrine on call service and/or KIDs service at Birmingham Children's Hospital based on the agreed Network statement. This advice is on a consultant-to-consultant basis.



# **Device Download Facilities (H3)**

Out-patient services are based at Worcestershire Royal Hospital, Kidderminster General Hospital and the Alexandra Hospital, Redditch. At each out-patient clinic visit, data from glucometers, insulin pumps and flash/continuous glucose monitoring systems can be downloaded/reviewed by the PDSN's so information is available to all members of the MDT whether seeing the patient separately or during a joint consultation. This is achieved by using the Medtronic Carelink, Glooko, Diasend, Libre and Dexcom Clarity systems.

Patients are encouraged to regularly download at home using the appropriate software for their device; the MDT are able to review the information remotely or through email and give advice as required.

# Point of Care Testing for HbA1c (H4)

On arrival to clinic CYP have their weight, height, and blood pressure measured and the clinic nurse takes a blood sample for point-of-care testing of IFCC HbA1c measurement. This is available in all clinic settings and the results are available for the consultation. The HbA1c is reported in both mmol/mol (IFCC) and % (DCCT) and is documented in the clinic notes and in the clinic letter (record of care) for CYP and their families. The result is also entered into the Twinkle.NET electronic database.

The point of care HbA1c Siemens DCA Vantage Analyzer machines are tested and calibrated every month. Three external quality assurance samples are distributed to each clinic every month (as detailed in laboratory procedure documentation) and are analysed as soon as possible upon receipt. Result forms are completed, and the results are entered onto the UK NEQAS EQA website for which the clinic nurses have log in details. The results forms are posted back to Adedoja Adeseye (Senior Biochemical Scientist) for storing. The biochemistry department accesses the results from the website and emails them to the named clinic nurses. Currently the UK NEQAS standards are complied with. Print outs can be provided as required. EQA for glucometers is covered in the Trusts' general SOP for glucose meters.

Siemens can be contacted if there are any concerns about the functionality of an HbA1c machine and they will organise a replacement machine if necessary.

# Riverbank Children's Ward Training (H5)

Healthcare professionals on Riverbank Ward are required to complete the 'National Curriculum for the Training of Healthcare Professionals Who Care for Children and Young People with Diabetes Mellitus' E-Learning: Level 1 Basic Awareness'. In addition to this, the PDSN's deliver a one day training session monthly. These sessions include teaching on diabetes care and competency sign-off. The training programme includes:

- What is diabetes and management of the newly diagnosed diabetic
- Safe use of insulin, which insulins are used and their actions, pumps versus injections
- Injection technique including
  - correct technique
  - same site same time of day
  - sites used/needle size
  - safety versus ordinary needles in learning demo
  - which insulin which site



- Blood glucose monitoring
- Normal blood glucose and ketone targets
- Management of hypos
- Ketone and glucose testing and when to test, management of DKA
- How to test teach families
- CareSens meter shown and given an idea of how used ratios/corrections with brief demo
- Advice on appropriate meals and snacks post diagnosis and while in hospital
- Level 3 carbohydrate counting for all children and a reminder about the Carbs and Cals book
- Snacks under 15 g (5 10g for children <7 years) or low CHO snacks between each meal for patients on injections
- All snacks on pumps must be bolused for unless hypo or exercise related
- The care of children and young people with diabetes undergoing surgery
- Discharge home check list
- TTO's:
  - sharps box
  - spare Echo pen device
  - who to contact for advice and support
  - consider Orchard service
  - information pack including blood glucose and food diaries
  - hypo treatment: brief review of what a hypo is, common symptoms and basic treatment including glucose gel and protocol for the unconscious CYP
  - team information and where to find new patient packs and ward information folder

#### Hand-outs

- Locality service patient information sheets for each area
- Back page tick list re discharge from newly diagnosed guideline
- The Diabetes UK family information booklet plus the BD good injection booklet

#### **Link Nurses**

In addition to these sessions, there are 2 half day training sessions for the ward's diabetes link nurses.

#### Community

The Paediatric Diabetes Nurses hold annual training days for acute and community staff involved in diabetes as well as undergraduate nursing students. They also do training sessions tailored to individual groups such as the Orchard Service and Specialist School Nurses. In addition, the PDSN's take part in a joint Paediatric Specialist Nurse training day which health visitors and school nurses are invited to attend. Education sessions for school staff are also held twice a year.

#### **Medical Trainees**

Paediatric medical trainees receive training about Diabetes emergencies:

- Dr West and Dr Hield deliver a diabetes update session at the paediatric departmental teaching on an annual basis.
- A training session on diabetes is held for all junior doctors in the department during their attachment.
- Dr West and Dr Hield also take part in paediatric GP study days (approximately alternate years).

Trainees are encouraged to attend the diabetes MDT clinics to reinforce and build on existing knowledge.

The Riverbank Ward Manager keeps an electronic record of staff attendance at ward training sessions as well as hard copies of staff competencies. Jodie Smith (Clinical Nurse Educator for Riverbank Ward)



keeps a record of the training programmes and the attendance of nurses and Dr West keeps a record for medical trainees.

# **Outpatients' Consultation Time (H6)**

The MDT (no clinical psychologist present for Wednesday morning or afternoon clinics at Worcester) meet 30 minutes before the first patient's appointment to discuss all patients on the clinic list. Each patient is discussed, and information shared including the plan from the last clinic appointment, an update on contacts since then, psychosocial factors, outstanding screening required and any other issues which may be relevant to the consultation.

All clinic appointments are scheduled for 30 minutes and the CYP and their carer see the consultant/specialist doctor, PDSN and dietitian at the same time. There is sufficient time in both the morning and afternoon clinics for reviewing device downloads, interpretation of results and discussions to gain a clear picture of the current situation. A clinical psychologist is present for some clinics but also reviews the patient lists for other clinics with the rest of the MDT to see if they have (or the patient is likely to need) any ongoing input which they need to share. CYP and their carers attending clinics when a clinical psychologist is not present are signposted to clinical psychology as required. CYP over the age of 13 are offered the chance to be seen on their own before a joint consultation with their carer.

### **CYPD MDT Measures**

### Leadership arrangements and responsibilities (M1)

Dr James West and Dr Corinne Hield are the clinical leads for the children and young people's diabetes MDT and have 0.5 PA's each per week (included in PA's in table below) for being Lead clinicians of the service.

#### The Lead Clinicians' responsibilities include:

- Taking overall responsibility for and leading the clinical activity of the MDT, working to agreed guidelines, ensuring a high-quality integrated service which meets local, regional and national targets
- Ensuring Best Practice Tariff criteria are achieved
- Submitting data to the National Paediatric Diabetes Audit annually
- Overall responsibility for ensuring the MDT works towards meeting peer review quality measures
- Attending and contributing to the West Midlands Paediatric Diabetes Network (WMPDN) meetings or sending a representative
- Ensuring clinical management guidelines are produced, approved by the WMPDN and kept up to date
- Reviewing the audit programme and completing audit and performance reports required by the Trust and WMPDN
- Leading on service improvement which includes liaising with commissioners
- Coordinating the regular review of the MDT action log and making sure the countywide meeting minutes are recorded and acted upon
- Leading countywide paediatric diabetes MDT meetings (along with meeting chair) and feeding back action plans to the Quality Improvement meeting
- Investigating Datix's related to paediatric diabetes and responding to patient safety incidents



- Liaising with the PDSN's and diabetes link nurses to ensure paediatric nursing competencies are up to date
- Delivering regular diabetes education sessions for junior doctors and an annual update for consultants
- Recognising and responding to issues of Safeguarding Children
- Attending Worcestershire Diabetes Network and Worcestershire Diabetes Interest Group meetings when able
- Overseeing the professional development of multidisciplinary team members
- Meeting a good standard of Continuing Professional Development
- Producing annual reports and work plans



# **Core Membership (M1)**

Role	Name	Title	Start date in	Qualification	Date	PA/WTE
			service			
Lead clinicians for the CYPD MDT	Dr James West	Consultant Paediatrician	Jun 2015	Level 3 training diabetes SPIN module	2015	2.2
the CIFD WD1	Dr Corinne Hield	Consultant Paediatrician	Mar 2023	RCPCH Specialist Interest Module (SPIN) in Diabetes	2022	2.0
Doctors	Dr Jessica Dale	Specialist Doctor	Nov 2021	Children and Young Peoples' Diabetes Care Module- Birmingham City University	2023	1.0
Nurses	Becki Walling	Lead PDSN	Jun 2020	BA (Hons) Nursing Management of Childhood Diabetes, Birmingham City University	2002 2015	1.0
	Esther Anstey	PDSN	Aug 2002	BSc Hons Community Paediatrics Management of Childhood diabetes in home and community, Independent Nurse Prescriber.	1999	1.0
	Jane Francis	PDSN	Jul 2012	Diploma in Children's Nursing Paediatric Diabetes Course	1999 2006	0.8
	Lee-Ann Edwards	PDSN	May 2016	Diploma in Nursing Paediatric diabetes course level 6	2018	0.6
	Siobhan Nangle	PDSN	Mar 2022	Dip HE Nursing Child Branch MSc Module in Children and young peoples diabetes care	2003 2023	0.8
	Chloe-Holden Jones	PDSN				
Dietitians	Dorota Amador Bueno	Lead Paediatric Diabetes Dietitian	Aug 2012	BSc in Dietetics, University of Natal, South Africa	2000	1.0
				MSc in Dietetics and Human Nutrition, University of Warsaw, Poland	2005	



				NHS Trust		
				Certificate in Diabetes Care, University	2004	
				of Warwick		
				Certificate in use of Insulin Pump	2004	
				Therapy, Royal Liverpool University		
				Hospital		
	Prinith de Alwis	Paediatric Diabetes	Aug 2023	BSc Dietetics - Coventry University	2006	0.6
	Jayasinghe	Dietitian		MSc Diabetes in the Young module	2021	
				University of Southampton		
Clinical	Dr Amy Symonds	Principal Clinical	Sep 2022	Doctorate in Clinical Psychology,	2018	0.4
psychologists		Psychologist		University of Birmingham		
				BSc Hons Psychology with placement	2011	
				year, University of Surrey		
	Dr Victoria Smalley	Clinical Psychologist	Jun 2021	Systemic family psychotherapy	2018	0.55
				intermediate level, Birmingham		
				Doctorate in Clinical Psychology	2012	
				including Foundation level training in		
				Systemic family psychotherapy,		
				University of Plymouth		
				MA Psychology, University of Surrey	2000	
				BA (Hons) Psychology, University of	1998	
				Wales, Cardiff		
Administration	Sarah Dent	Paediatric secretary,	Aug 2020			0.75
support		data entry clerk				

#### Cover for absence:

• The PDSN service has a system in place to cover absence which is clearly communicated to patients and staff by means of answer phone messages and out-of-office email replies.



Extended Team	Name	Job Title
Link for child safeguarding	Laura Phipps/Sam Dixon	Named Nurse for Safeguarding
Inpatient ward link nurse	Sharon Lownsbrough	Sister
	Emma Barton	Staff nurse
Podiatrist	Ann Bateman	Podiatrist
Diabetes clinician for adult services and responsible for transition	Dr Irfan Babar	Adult consultant diabetologist
Clinic nurse and link nurse lead – WRH	Marie Welch	Staff nurse
Clinic nurse and link nurse lead – Alexandra Hospital	Sarah Weale	Sister
Clinic nurse and link nurse lead – KTC	Beverley Darbyshire	Staff nurse
Consultant secretarial support	Sarah Scotford	Paediatric secretary
	Demi Clark	Paediatric secretary



#### **Responsibilities of Core Nurse Members:**

- Contribute to multidisciplinary team and patient assessment/care.
- Provide specialist educational and training support to patients, parents, and schools, promoting holistic care.
- Provide link nurse responsibilities to their named patients, contributing towards high HbA1c meetings and informing team of specific problems.
- Liaising with key workers, including schools, on behalf of their patients.
- Contribute towards the efficient management of the team, completing templates and utilising new ideas and research as discussed by the team.
- Contribute towards audit.
- Acting as advice and an expert resource for other professionals.
- Maintain an up-to-date knowledge base and understanding all aspects of diabetes care and how it relates to dietetics and healthy living.

#### **Responsibilities of Core Dietitian Members**

- Contribute towards multidisciplinary discussions and patient assessment/care.
- Provide expert, evidence based, practical and culturally appropriate dietetic advice at diagnosis, including the education required to allow the CYP and their carers to self-manage diabetes at home
- Lead on the education of the dietary management of diabetes, physical activity and carbohydrate counting for CYP, parents and carers as well as MDT members, other healthcare professionals, ward and clinic staff.
- Undertake assessments of nutritional status, growth and dietary intake and provide individualised nutritional advice to promote healthy growth and development and prevent development of nutritional deficiencies.
- Teach CYP and their carers how to adjust insulin doses according to blood glucose levels and carbohydrate intake and provide guidance on the nutritional management for CYP using insulin pump therapy and hybrid closed loop systems.
- Interpret blood glucose monitoring results, including flash/continuous glucose monitoring, and provide appropriate advice to reduce hypo- and hyperglycaemia.
- Provide specific and individualised dietary advice on various conditions, including coeliac
  disease, cystic fibrosis, type 2 diabetes, other types of diabetes and insulin resistance, weight
  and lipid management, gastro-intestinal problems, as well as restrictive or fussy eating and in
  specific nutritional deficiencies, food allergies or intolerances.
- Apply skills in behavioural change techniques and positive parenting skills training to help CYP to achieve individualised nutrition targets and implement principles of healthy eating and optimise blood glucose control.
- Educate CYP, families, other healthcare professionals, teachers and coaches on exercise management including advice on carbohydrate intake and advances in insulin management.
- Provide advice on diet, carbohydrate management and insulin dose adjustment during illness and periods of fasting for religious reasons.
- Recognise signs and symptoms of emotional distress or behavioural difficulties that require a referral to the Clinical Psychologist or other mental health services.
- Work with the MDT to achieve the most appropriate care/action plans if there are safeguarding concerns about the child's welfare.
- Recognise and manage abnormal, dysfunctional, controlled eating behaviours and make appropriate referrals.
- Participate in the planning of transition from the CYP service to adult services.
- Coordinate additional dietetic appointments, keep records according to departmental standards and liaise with the MDT to arrange suitable follow up.



- Produce and update nutritional information patient leaflets, carbohydrate counting aids and information on exercise management.
- Participate in strategic plans to improve services and contribute to the development and review
  of departmental guidelines and policies and attend the MDT and Network meetings and training
  days.
- Participate and contribute to service evaluation and audit to continue to improve dietetic service provision.
- Develop and evaluate age appropriate and theory-based teaching packages for small and large groups of CYP and families, such as structured education workshops and the other events organised by the team.
- Advise schools on dietary management of diabetes, particularly in relation to school menus and contribute to school training programs.
- Maintain an up-to-date knowledge base and understanding of all aspects of paediatric dietary management and paediatric diabetes care and how it relates to dietetics, complication management and healthy living.

#### **Responsibilities of Clinical Psychologists Core Members:**

- Contribute towards multidisciplinary discussions and patient assessment/care.
- Provide specialist assessment of mental health and psychological wellbeing in CYP and their families and direct psychological interventions in relation to psychosocial aspects of living with diabetes.
- Signposting and referral on to local and regional mental health and social care services.
- Coordination of annual screening for psychological and emotional well-being in CYP and their families.
- Provision of consultation and advice to MDT members and other professionals from external agencies in relation to psychosocial adjustment.
- Teaching/training of MDT members in psychological principles/approaches to support members in their care of patients.
- Ongoing service development in line with relevant policies/guidance to enhance the overall psychological care provided to families.
- Development of information resources available to children and families in relation to psychological and emotional well-being.
- Participation in service evaluation and audit to further improve psychological care and incorporate patient-rated experience.
- Contribute to wider team patient activities e.g. structured education events.

### Responsibilities of Data Clerk/Administrator:

- Act as data administrator for the team.
- Support the team in ensuring accurate data is collected and validated by clinicians.
- Review clinic capacity and highlight available appointments.
- Format, photocopy and send newsletters and invitations for structured education events, the activity weekend, teen event, BBQ/tea and cake event and Xmas party.
- To enter patient contacts into Oasis.
- Arrange resources for structured education days e.g. handouts.
- Book rooms and organise calendar invites for meetings and take minutes.
- Send appointments using existing Bluespier templates.
- To undertake photocopying and document collation of patient information leaflets, questionnaires and education resources as required. To ensure there are enough psychology questionnaire packs for annual screenings.
- Liaise with admin who can use Iproc to order, track and distribute questionnaires as requested.



• To type dictations/correspondence for the Clinical Nurse Specialists, Dietitians and Clinical Psychologists as required.

### **Ongoing Specialist Training (M1)**

Initial training to qualify as a core member is listed in the core membership table above. The most recent Continuing Professional Development for those considered exempt will be itemised in the MDT's Annual Report.

All staff are encouraged to attend a training/conference at least once a year in their field of practice. At least 1 member (usually 2-3) of the MDT attends each West Midlands Paediatric Diabetes Network meeting which has an educational element. Dr West is also on the Steering Committee for the Network.

# **Clinical Guidelines (M3)**

The team works within the NICE (2023), ISPAD (2022) and BSPED (2021) guidelines in all aspects of diabetes management. The guidelines in use are detailed in the table below:

Guideline	Guideline	Date last reviewed	Date agreed
	Reference		by/endorsed
	Number (if		by CYPD
	applicable)		, Network
Care of children and young people newly diagnosed with diabetes, including that, for Type 1 diabetes, children and young people from diagnosis must be offered insulin therapy with multiple daily injections (MDI) and Level 3 carbohydrate counting.	WAHT-PAE- 063	May 2024	Jun 2018
Care of children and young people with diabetes undergoing surgery.	WAHT-PAE- 073	Feb 2024	Jun 2018
Care of children and young people with diabetic keto-acidosis (DKA).	WAHT-PAE- 037	Feb 2024	Jun 2018
Care of children and young people with hypoglycaemia.	WAHT-PAE- 083	Feb 2024	Jun 2018
Care of children and young people with an HbA1c greater than 69 mmol/mol (8.5 %).	WAHT-PAE- 103	Extended for 6 months from Feb 2024	Jun 2018
Sick day rules.	WAHT-PAE- 039	May 2024	Jun 2018
For Type 1 diabetes, the option of continuous glucose monitoring (either on-going or intermittently) should be offered to patients who meet the NICE	WAHT- PAE- 149	Feb 2024	Jun 2018



criteria.			
Failure to Attend for Children and Young People with Diabetes	WAHT-TP- 045	Extended for 6 months from Feb 2024	Jun 2018
Paediatric & Adolescent Diabetes	WAHT-TP-	Extended for 6 months	Jun 2018
Transitional Care	086	from Feb 2024	
Continuous Glucose Monitoring Guideline	WAHT-PAE-	Extended for 6 months	
for Children and Young People with	149	from Feb 2024	
Diabetes			
Insulin Pump Therapy Guideline	WAHT-TP-	Extended for 6 months	
for Children and Young People with	045	from Feb 2024	
Diabetes			

Dr West is informed by the NICE and Key Documents Support Officer if a guideline or patient information leaflet is due to expire (all documents are reviewed every 3 years). The document will then be reviewed and updated as necessary before being submitted to the Quality Improvement Meeting for final approval. All clinical guidelines are available on the Paediatric page of the Trust's pathways on the Intranet.

### Patient Pathways (M4)

#### Newly Diagnosed Diabetic Pathway

The West Midland Paediatric Diabetes Network referral pathway for newly diagnosed patients in primary care was circulated to the Chair of the Worcestershire Diabetes Network as well as the Quality Improvement Meeting for comments before onward distribution to the CCG's in March 2018. An updated version was sent to the CCG's in January 2020.

If a CYP has type 1 symptoms and is thought to have newly diagnosed T1DM they are referred to the on call paediatric doctor on bleep 676 either by their GP or the Emergency Department. If a newly diagnosed patient referred by their GP is felt to be in DKA or clinically unstable they are asked to attend the ED for stabilisation before transfer to Riverbank Ward (the ED are informed that the patient is attending and asked to contact bleep 676 when the patient arrives). If in DKA, the BSPED DKA guideline (WAHT-PAE-037) is followed.

Once on Riverbank Ward guideline 'WHAT-PAE-063: Guidance on Management of Children and Young People with Newly Diagnosed Type 1 Diabetes' is used and the structured education process begins. All CYP (including those between 17-18 years of age who choose to be admitted to an adult ward) are discussed with the Paediatric Diabetes Team (either consultant or PDSN) within 24 hours of diagnosis before they are reviewed by the Paediatric Diabetes MDT on the next working day. The GP is informed of the newly diagnosed CYP via the electronic discharge summary by the end of the second working day post discharge.

Following discharge, the CYP and their carers receive a programme of structured education which includes daily (not including weekends) contact with the PDSN's and/or the dietitians. They also have support from the Orchard (Community) Nursing Team at weekends and Bank holidays.



#### **DKA Pathway**

All CYP with suspected DKA are referred to the paediatric doctor oncall on bleep 676. Patients referred by their GP or self-referrals of known diabetics are asked to attend the ED for stabilisation before transfer to Riverbank Ward. Patients are then managed in accordance with the 'WAHT-PAE-037 BSPED DKA guideline' using the 'WHAT-TP-045 BSPED Integrated care Pathway for the Management of Children and Young People with Diabetic Ketoacidosis'. It has been jointly agreed with the adult diabetes team that all CYP (including 16-18-year olds) are admitted to Riverbank Ward to ensure the BSPED DKA protocol is followed (although this patient group may initially be managed using the local adult guideline in ED if the ED team are more familiar with this). For known diabetics, overall self-management and precipitating causes are reviewed to try and prevent recurrence.

#### Hypoglycaemia Pathway

CYP and their carers are given clear guidance on how to manage hypoglycaemic episodes in accordance with 'WAHT-PAE-083 Paediatric Hypoglycaemia Guideline for Children with Type 1 Diabetes'. If a patient is conscious and able to tolerate oral fluids they should try self-treatment twice using rapid-acting glucose. If the CYP is uncooperative but conscious then a carer can try Glucogel. If these treatments are not effective in raising the blood glucose level ≥4 mmol/l, or the child is unconscious or fitting and outside of hospital then the emergency services should be called. If in hospital, then the paediatric doctor on call on bleep 676 should be called. If IV access is available treatment with up to 5 ml/kg of 10% dextrose as a slow IV bolus is given. If no IV access is available, glucagon can be given intramuscularly or subcutaneously into the thigh. The CYP is admitted to Riverbank Ward for ongoing monitoring and treatment. Referral to the diabetes team is made for review of treatment, advice and education.

Pathway	Pathway	Date last	Date
	Reference	reviewed	agreed by
	Number (if		/endorsed
	applicable)		by CYPD
			Network
Referral of the newly diagnosed patient	See appendix	Feb 2024	Jun 2018
(aimed at primary care and general	5 as well as		
paediatric services); including that a child	guideline:		
or young person with a new diagnosis of	WAHT-PAE-		
diabetes is discussed with a senior	063		
member of the children and young			
people's diabetes team within 24 hours			
of presentation to hospital.			
That all new patients must be seen by a	See appendix	Feb 2024	Jun 2018
member of the specialist paediatric	5 as well as		
diabetes team on the next working day.	guideline:		
	WAHT-PAE-		
	063		
Management of complications of	See appendix		Jun 2018
diabetes including DKA and	5 as well as		
hypoglycaemia.	guideline:		
	WAHT-PAE-	Feb 2024	
	037		
	WHAT-PAE-	Feb 2024	



	083		
--	-----	--	--

Patient Pathways in Appendix 5.

### **Primary Care Communication (M5)**

GPs are informed about newly diagnosed diabetics by the electronic discharge summary (EDS) generated by the patient's admission. Clinical guideline WAHT-PAE-063 'Guidance on the management of children and young people with newly diagnosed type 1 diabetes' includes a checklist for completion by the paediatric doctors on the ward. One of the discharge items is 'patient should not be discharged before GP letter/EDS is complete'. Patients are discharged with the medication and equipment they need for the initial few weeks post diagnosis and the PDSN's send a newly diagnosed letter to the GP informing them of what needs to be included on repeat prescriptions.

Failure of same day referral of a newly diagnosed type 1 diabetic will be reported and investigated as a clinical incident. If there has been a delay in diagnosis or referral, this is fed back to the manager of the practice involved for discussion, reflection and shared learning at their practice meeting.

Letter Template to GP in Appendix 6.

### Patient Choice of Insulin Pump Therapy (M6)

Continuous subcutaneous insulin infusion (CSII) pump therapy is offered to all CYP across the service who fulfil the NICE Technical Assessment (TA151) criteria as an alternative to multiple daily injections. Currently we do not routinely start newly diagnosed CYP on insulin pump therapy.

See PAGE 20-21 for flow chart regarding patient journey from assessment to initiating insulin pump therapy and follow-up

CYP on pump therapy attend the usual multidisciplinary clinics. They are encouraged to download their insulin pump and review their data prior to attending clinic however, facilities are available in all three clinics to download insulin pumps or review data online. CYP and their carers are encouraged to be in regular contact with the PDSN's by phone or email to assess pump downloads along with flash/continuous glucose monitors and optimise management in between clinic appointments.



### **Paediatric Diabetes Insulin Pump Pathway**

# <u>Does the patient meet any of the three NICE</u> (2008, TA151) criteria?

- 1: Attempts to reach target HbA1c of ≤58 mmol/mol leads to disabling hypoglycaemia (see below).
- 2: HbA1c ≥69 mmol/mol with MDI treatment despite the person carefully trying to manage their diabetes.
- 3: If treatment with multiple daily injections is not practical or not considered appropriate.

Disabling hypoglycaemia (TA151):
Disabling hypoglycaemia is when
hypoglycaemic episodes occur frequently or
without warning so that the person is
constantly anxious about another episode
occurring, which has a negative impact on
their quality of life.

Impaired hypoglycaemia awareness (Clarke 1995)

Hypoglycaemia Fear Survey – Worry sub scale (Cox et al, 1987).

#### **Initial assessment**

- 1 Baseline information collection
  - HbA1c
  - Hypo awareness questionnaire
  - Fear of hypo questionnaire
  - Document why patient meets NICE TA151 criteria
- 2 Agree and document goals for 6 months
  - HbA1c target
  - Reduction in hypoglycaemia score if appropriate
  - Quality of Life
- 3 Outline team expectations of patients and families when going on a pump
- 4 Family/CYP to complete dietetic review/ further input by dietitian on carbohydrate counting if required
- 5 Two dates for pump training agreed in a group or individual setting if circumstances dictate, together with a date for supporting first set change

#### **Group or individual start preparation**

- 1 Order pump via diabetes lead nurse for group and set up patient account
- 2 Send GP letter informing of pump start and to obtain prescription for:
  - Ketone strips
  - 10 ml vial of chosen insulin
  - Countour test strips (Medtronic)
  - Quick acting pen
  - Long acting pen
- 3 Send patient letter detailing dates of education, ask them to collect prescription and advise on what to do with background insulin dose prior to start
- 4 Work out settings via starting dose calculator

#### Group or individual session 1

- 1. Complete audit tool and pump agreement
- 2. Principles of pump therapy and functionality of pump
- 3. How the pump works & setting up insulin pump with personalised settings
- 4. Infusion site management
- 5. Hyperglycaemia and ketone management and conversion back to MDI in emergencies
- 5. Setting up Carelink account (Medtronic), pump data downloading (other pumps)
- 7. Hypoglycaemia management
- 8. Arrange a download and follow up phone/visit for titration and first set change



#### Group or individual session (2 -4 weeks post start)

Download pump to assess progress and titrate doses

#### Education on:

- Advanced bolus options
- Travel and safety information
- Basic guide to exercise
- Arrange download and phone follow-up
- How to assess and make changes at home by interpreting reports on data available
- How to manage alcohol on pump therapy
- Testing and modifying basal rates
- Testing and modifying carbohydrate ratios
- Arrange further download and follow-up

#### 3-month assessment

Download pump at clinic (or families do before if able)

Repeat baseline measurements and complete audit tool

- HbA1c
- Hypo awareness questionnaire

Have goals been met?

Yes - continue with pump therapy

#### No consider:

- 1. Time extension to achieve goals
- 2. Pump holiday for 2 weeks and reassess
- 3. Return to injections



# **Continuous Glucose Monitoring (CGM) (M7)**

Continuous glucose monitoring is offered to all CYP with type 1 diabetes in line with the NICE guideline (NG18) 'Diabetes (type 1 and type 2) in children and young people: diagnosis and management'. Intermittently scanned (flash) glucose monitoring using the Freestyle Libre device is also offered to CYP who are unable to tolerate CGM. Please see guideline 'WAHT- PAE-149 Continuous Glucose Monitoring Guideline for Children and Young People with Diabetes' for further information. Group or individual structured education is delivered to CYP and their carers when commencing CGM or FGM. Information can be downloaded alongside the insulin pump both at home and in the clinic setting.

In addition, professional CGM is carried out by the PDSN's on occasions for diagnostic/monitoring purposes.

### **Hybrid Closed Loop Systems**

An insulin pump, as part of a hybrid closed loop system (in automode), automatically adjusts the basal insulin rate and gives correction doses based on the information on glucose level and trends sent from the continuous glucose monitor. At times of carbohydrate consumption, the child will give an insulin bolus using their insulin to carbohydrate ratio to work out how much is needed.

Following release of NICE TA943 Hybrid closed loop systems for managing blood glucose levels in type 1 diabetes, the closed loop systems currently offered include the Omnipod 5 with Dexcom G6 CGM, Tanden T:slim Control-IQ with Dexcom G6 CGM and the Medtronic MiniMed 780G with the Guardian 3/4 CGM.

# Multidisciplinary Follow-Up Appointments (M8)

All CYP with diabetes across the 3 locality sites are offered a minimum of four multidisciplinary clinic appointments per year. At each appointment patients have their height and weight measured. They also have their HbA1c measured with results available in clinic to facilitate discussions on target blood glucose levels and HbA1c. CYP and their carers have the option of seeing the PDSN, dietitian and clinical psychologist (some clinics) but always see the consultant or specialist doctor. Insulin adjustment, dietary and lifestyle advice, dependant on the CYP's stage of development, are also provided. Individualised objectives are agreed, and ongoing education is performed with the use of the Goals of Diabetes educational package and documentation. Clinic letters are written to the CYP and their carers (copied to GPs) and serve as their personal health record and their copy of personal goals discussed.

Patient non-attendance to clinic is monitored by the clinic receptionist and if the patient cancels 2 consecutive appointments a letter is sent reminding the family of the national recommendation of 4 MDT clinic appointments per year. If a patient DNA's 2 consecutive appointments, social factors are considered, and a letter is sent stating that the patient will be referred to social care if they do not attend their next appointment. Please see guideline 'WAHT-TP-045 Failure to Attend for Children and Young People with Diabetes'.

Data is collected during clinic and entered into the Twinkle.NET electronic database. Missing data is collected throughout the NPDA year.



# **HbA1C Measurement (M9)**

All patients are offered a minimum of 4 MDT clinic appointments per year and at every clinic attendance patients are offered a HbA1c measurement. If a patient cancels or DNA's an MDT clinic appointment they are offered an additional opportunity to attend to have their HbA1c checked.

The HbA1c result is available in clinic to facilitate discussions on target blood glucose levels, HbA1c and to agree objectives. The results are recorded in the clinic notes, on the Twinkle.NET electronic database for monitoring and in the clinic letter to the CYP and their carer.

### **Dietetic Assessment (M10)**

The paediatric diabetes dietitians attend MDT clinics across the county; cover for annual leave is provided where possible.

At diagnosis a dietitian undertakes an assessment of nutritional status and dietary intake for all CYP and coordinates appropriate follow up to facilitate education on dietary management of diabetes and physical activity to promote healthy growth and development. This includes carbohydrate counting and insulin dose adjustment to achieve optimal blood glucose levels. The dietitian reviews the CYP and carers' carbohydrate counting skills and carbohydrate intake and sets the insulin to carbohydrate ratios based on blood glucose levels.

At MDT clinic appointments the dietitian conducts regular reviews of the CYP's nutritional status, growth and dietary intake. They also assess the CYP and their carers' understanding of CHO containing foods and different methods of estimating portion sizes and skills in insulin dose adjustment. The dietitian assesses the macro- and micro- nutrient intake and calculates carbohydrate requirements according to age, weight and activity levels. The dietitian reviews the changing carbohydrate intake and blood glucose levels and advises on insulin to carbohydrate ratios and correction factors. They also assess the management of physical activity and provide practical advice on appropriate carbohydrate intake and insulin dose adjustment for optimal blood glucose levels during and after physical activity.

In addition to the minimum of 4 MDT clinic appointments, where the CYP sees the dietitian, all patients are invited to make an additional appointment with the dietitian. Information about this additional appointment is included at the bottom of all clinic letters. Additional appointments are encouraged for patients requiring further support with carbohydrate counting and those with specific dietary needs such as a gluten free diet, weight/lipid management, restrictive or fussy eating or patients who need advanced advice for sport management. The dietitian arranges additional dietetic appointments and telephone/virtual follow-ups and keeps a record of CYP and their carers who take up this additional dietary assessment and counselling. The dietitian participates in group education provided by the MDT.

# **Psychological Assessment (M11)**

For detailed information on the referral pathway to clinical psychology please see the document:

Worcestershire Paediatric Diabetes Team (WPDT) – Psychology Service Pathway Overview

A clinical psychologist is present for some clinics but also reviews the patient lists for other clinics with the rest of the MDT to see if they have (or the patient is likely to need) any ongoing input which they need to share. CYP and their carers attending clinics when a clinical psychologist is not present are



signposted to clinical psychology if it is felt to be needed and they can make additional appointments with the clinical psychologist by contacting them directly.

The clinical psychologist oversees the administration of annual screening psychology questionnaires in the MDT clinic. They analyse the results and determine whether input from a clinical psychologist is warranted. In addition to more formal screening, the clinical psychologist is in regular discussions with the rest of the MDT to ascertain if and when further, more targeted psychological assessment or intervention would be helpful to the CYP. Families are made aware from diagnosis that they can contact clinical psychology directly at any stage.

### **Additional Contacts (M12)**

All patients are offered a minimum of eight additional contacts annually but most patients receive a lot more. These contacts are in addition to the MDT clinic visits and include telephone contacts, emails/texts, school visits, home visits, troubleshooting and a quarterly newsletter. Twinkle.NET and the Trust's patient administration system (Oasis) is used to document and monitor these contacts.

# Did Not Attend Policy (M13)

There is a policy for the CYPD MDT for the management of non-attenders. As mentioned above, patient non-attendance to clinic is monitored by the clinic receptionist and if the patient cancels 2 consecutive appointments a letter is sent reminding the family of the national recommendation of 4 MDT clinic appointments per year. If a patient DNA's 2 consecutive appointments, social factors are considered, and a letter is sent stating that the patient will be referred to social care if they do not attend their next appointment.

Dr West is responsible for the policy which was last revised in February 2024. It considers the Trustwide DNA/Safeguarding Policy and includes an assessment of any safeguarding concerns related to non-attendance, collaboration with other healthcare professionals and appropriate sharing of information (NB The Worcestershire Safeguarding Children's Board does not have a 'did not attend/was not brought policy'). DNA rates for different age bands across all clinics are discussed at the countywide meeting, action plans are developed and implemented. In addition, DNA/WNB rates are discussed annually at a West Midlands Paediatric Diabetes Network meeting. There is also a policy for CYP with high HbA1c's.

• WAHT-PAE-102: Failure to attend guideline

WAHT-PAE-103: High HbA1c guideline

# Support for Children in Education (M14)

PDSN's actively support and train school staff to deliver care and support to CYP with diabetes within nursery, school, academy and college settings. A guideline was written with the support of Worcestershire County Council to encourage good practice, clarify the roles of all parties and to ensure CYP with diabetes are supported to continue with their education. This has been available on the County Council's Children's Services Portal as well as within our own organisation since April 2018.

WAHT-PAE-085: Supporting children in schools – A document shared on the Children's Services
 Portal by Worcestershire County Council



#### This guideline includes:

- arrangements for liaison with schools and colleges
- agreement of a school care plan for each child which is reviewed at least annually
- visits to the school or college by a PDSN to discuss the care of each newly diagnosed child
- training and assessment of competences of school and college staff by the CYP's diabetes team (including school day trips and residential trips)
- storage of medicines while in school or college, including the safe disposal of sharps
- responsibilities of school and college staff for supervising the delivery of/or administering insulin and the supervising of/or testing of blood glucose levels
- guidelines on care of children with diabetes while in school or college
- carbohydrate counting of meals
- management of physical activity
- guidelines on the management of diabetic emergencies

Following feedback, school staff are offered the opportunity to attend a training day twice a year (4 sessions - am/pm) on convenient dates. Staff are also asked to complete the Digibete and JDRF schools e-learning modules. After providing us with a copy of their certificate, the PDSN will go in to school and sign off their competencies for injections, pump boluses, BG monitoring, use of Flash GM and CGM. We aim to get children back to school safely as soon as possible after diagnosis by ensuring that there are enough staff trained to support the child.

School care plans are written by PDSN's at the time of need and are updated on a yearly basis. Copies of these are contained in the nursing notes and on Bluespier.

# Screening of Children and Young People with Diabetes (M15)

CYP with diabetes are screened according to current NICE guidance.

#### In Type 1 disease, for:

- Coeliac disease at diagnosis this test is included under the 'new diabetic profile' tab on the electronic pathology request and reporting system. Newly diagnosed patients are reviewed in clinic 6 weeks post diagnosis at which point it is checked that testing has occurred to ensure it is performed within 3 months of diagnosis. Following diagnosis patients are tested on an annual basis and this is monitored by the clinic nurses. Results are automatically entered into the Twinkle electronic database.
- Thyroid disease at diagnosis and annually thereafter until transfer to adult services this test is included under the 'new diabetic profile' tab on the electronic pathology request and reporting system. Newly diagnosed patients are reviewed in clinic 6 weeks post diagnosis at which point it is checked that testing has occurred to ensure it is performed within 3 months of diagnosis. Patients are then tested on an annual basis. This is monitored by the clinic nurses and entered into Twinkle.
- Retinopathy screening biannually from the age of 12 years CYP are referred to their local
  retinopathy screening service at 12 years of age. Retinopathy screening results are obtained
  from the Health Intelligence system and entered into Twinkle for monitoring. Patients are
  provided with the retinopathy screening service contact details to make an appointment if they
  are due a review.
- Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol;
   'microalbuminuria') from the age of 12 years from the age of 12 years all CYP are asked to provide a random urine sample on an annual basis. This is monitored by the clinic nurses and



- entered into the Twinkle electronic database. If a patient has a high ACR, two early morning urine samples are requested to confirm or exclude micro/macroalbuminuria.
- **Standard anthropometric data** all patients have their height and weight measured at each clinic appointment. This data is entered into Twinkle for monitoring.
- Blood pressure annually from the age of 12 years all CYP 12 years or older have their BP measured electronically on an annual basis. If this result appears abnormal, it is confirmed manually. If the readings are still high, the patient is asked to attend their GP for it to be measured and if still high ambulatory BP monitoring is performed. The results are entered into Twinkle for monitoring purposes.
- **Dyslipidaemia annually from the age of 12 years** a blood test for a lipid screen is performed by the clinic nurse annually. The result is entered into Twinkle for monitoring.
- Foot assessment/examination all CYP 12 years or older have their feet examined to monitor for complications. This is entered into Twinkle for monitoring. Children under 12 years of age are offered foot care advice.
- Formal assessment of psychological wellbeing this is performed with the use of specific CYP
  questionnaires to determine if further input from the clinical psychologist is needed and to
  guide access to psychological support. This complements regular and ongoing psychological
  assessment by psychologists and the MDT.

#### In Type 2 disease, for:

- **Hypertension annually starting at diagnosis** BP is measured at diagnosis and at least annually by the clinic nurse. The result is entered into Twinkle for monitoring.
- Dyslipidaemia annually starting at diagnosis a blood test for a lipid screen is performed by the clinic nurse at diagnosis and annually thereafter. The result is entered into Twinkle for monitoring.
- Retinopathy screening biannually from the age of 12 years CYP are referred to their local
  retinopathy screening service at 12 years of age. Retinopathy screening results are obtained
  from the Health Intelligence system and entered into Twinkle for monitoring. Patients are
  provided with the retinopathy screening service contact details to make an appointment if they
  are due a review
- Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol;
  'microalbuminuria') from diagnosis all CYP are asked to provide a random urine sample at
  diagnosis and annually thereafter. This is monitored by the clinic nurses and entered into the
  Twinkle electronic database. If a patient has a high ACR, two early morning urine samples are
  requested to confirm or exclude micro/macroalbuminuria.
- Formal assessment of psychological wellbeing this is performed with the use of specific CYP questionnaires to determine if further input from one of the clinical psychologists is needed and to guide access to psychological support. This complements regular and ongoing psychological assessment by psychologists and the MDT.

# **Transition and Transfer Policy (M16)**

A transition guideline is in place to formalise the transition process. Prior to transfer the young person attends a joint clinic appointment with the paediatric and adult diabetes nurses. The PDSN will try and attend the patient's first appointment in the adult clinic if possible.

As well as documenting the patient journey there is also a pathway document which is held in the nursing records to record educational updates, assess if a young person is vulnerable and identify key



workers in the paediatric and adult diabetes teams on transfer. The Goals of Diabetes programme of competencies is used to develop safe self-management of diabetes care prior to transfer. The decision to transfer a patient is based on the young person's physical development, emotional maturity, local circumstances and patient choice. Those with additional or complex needs have individualised transition and transfer arrangements agreed. There are also leaflets on transition for the young people and their parents. A video on transition involving young adults describing their concerns and experiences has been produced and is on the Trust's website.

WAHT-PAE-086: Transition

Young women attending clinic who become pregnant are immediately referred to the adult diabetes team and obstetric/midwifery services for expert management of their pregnancy.

Following the 2020 RCPCH external peer review, a transition working group was formed consisting of members of the paediatric and adult diabetes MDT's. A business case was written with the help of the ICB to try and improve the transition and transfer process. The overall aim is to introduce young adult diabetes clinics and transition nurses to maximise patient engagement and minimise the number of patients lost to follow-up. The lack of a young adult diabetes clinic is on adult medicine's risk register.

As mentioned in the DKA pathway section, it has been jointly agreed with the adult diabetes team that all 16-18-year-olds are admitted to Riverbank Ward to ensure the BSPED DKA protocol is followed.

• WAHT-PAE-037: BSPED DKA guideline

# Key Worker (M18)

Each CYP is allocated a key worker at diagnosis. This key worker is the first PDSN that the CYP meets from their locality. Because 2-3 PDSN's oversee the CYP in each locality, patients can contact the other PDSN when their keyworker is not available. The CYP and their carers are informed of this at diagnosis, and it is documented in the nursing notes. This keyworker remains the same during transition and is the PDSN that attends the joint appointment with the adult DSN and the young adult's first adult clinic appointment.

# Patient Information and Support (M19)

All families receive an A4 folder with information about diabetes (based on the Diabetes UK starter pack) on diagnosis. All leaflets are approved at the Paediatric Quality Improvement (governance) meeting. Age/maturity appropriate written information on individual subjects and educational resources are provided as the CYP progresses through their educational journey.

These leaflets can also be used to top-up educational topics. Some information leaflets used are from the insulin company Lilly which have been designed and approved by the RCN special interest group in diabetes.

As per Trust policy all information is available in different formats (such as Braille or easy read) and languages by contacting Patient Services. CYP and their carers can also access patient information leaflets via the Trust's website.

There is also written information on how to make a complaint or a compliment.



Information	Local or Nationally	If included in other	Data
Information	Local or Nationally		Date
	produced	documents identify	revised/
District description of the		which	published
Brief description of the	Local		Jun 2020
condition and its impact			
Treatments available	Local and national		Jun 2020
(pharmacological and non-			
pharmacological)			
Management of high and low	Local and national		Jun 2020
blood glucose crises	Also GlucaGen leaflet and		
	instructions		
Management of diabetes	Local and national –	Also, Lilly leaflet	Jun 2020
during times of illness,	separate leaflets for MDI,		
including 'sick day rules'	IPT and BD insulin		
	patients		
Nutritional advice	Local		Oct 2020
	Initial nutritional advice		
	Snacks		
	Carbohydrate counting		
	Local		Apr 2017
	Healthy Eating		
	Carbohydrate counting		
	Insulin Dose Adjustment		
Local arrangements for	Local		Jun 2020
sharps disposal			
Psychological well-being	Local and national	Lilly leaflet on	Jan 2018
	A leaflet on the paediatric	Emotional	
	diabetes psychology	Wellbeing	
	service.		
	A leaflet on Emotional		
	wellbeing		
Disability living allowance	Local		Jun 2020
advice			
Travel advice	Local and national	Lilly leaflet	Jun 2020
Possible complications and	Local		Jun 2020
how to prevent these			
(including vaccinations)			
Information on local support	Local	Out-of-hours info	Jun 2020
groups on paediatric		leaflet	
diabetes if available			
What to expect at annual	Local		Jun 2020
review			
Description of the steps in	Local		Jun 2020
the transition process to			
adult care			
The opportunity for peer	Local		Jun 2020
support to young people			
during the transition process			



to adult care			
Where to go for further	Local		Jun 2020
information, including useful			
websites and books			
Lifestyle advice, including	Local and national	Lilly leaflets	Jun 2020
physical activity, smoking			
cessation, use of alcohol and			
recreational drugs, sexual			
health and contraception,			
pre-conception care and			
driving (where applicable)			

Initial information provided at diagnosis:

- Paediatric diabetes service information (locality based) leaflet
  - Redditch
  - Worcester
  - Kidderminster
- What is diabetes?
- Healthy eating with diabetes initial advice for young people with diabetes includes simple hypo/exercise treatment
- Disposal of sharps
- How to look after my diabetes at school
- Insulin injections
- Hypo management included in WAHT initial dietary leaflet, BD and Lilly leaflets
- Exercise included in WAHT dietary leaflets and Lilly leaflets
- BD Growing up with diabetes or teenage version Living with Diabetes (includes hypo information)
- Blood glucose monitoring
- Receiving a good service from your paediatric diabetes team
- Paediatric diabetes psychology service
- Out-of-hours and other resources
- Pen user device leaflets
  - Novonordisk Novopen Echo
  - Novonordisk Novopen 5
  - Aventis Solostar/Flexpen

Deapp and the associated tools are also available to help with education of the newly diagnosed diabetic and their carers. It can also be used for ongoing education of our CYP and during restabilisation when patients are admitted to Riverbank Ward.

Additional information given during the initial weeks following diagnosis:

- Second dietary advice leaflets Healthy eating, Carbohydrate Counting, Insulin dose adjustment and Carbohydrate Counting Tables
- Flu vaccine
- HbA1c
- Illness management
- Illness management on pump therapy
- Wearing identification
- What happens on clinic days



- Annual review
- Complications
- Disability living allowance
- Footcare
- Holidays
- Glycaemic index dietitian to give if appropriate
- Sport and Exercise dietitians or PDSN's to give own specific leaflet or use Gwent Healthcare booklet for the very sporty
- GlucaGen leaflet and instruction

#### Teenage leaflets and topics when appropriate:

- Diabetes and Careers
- Driving
- Exams and stress
- Smoking

#### Lilly Streetwise series:

- Safe drinking
- Drugs
- Sex and beyond
- Body piercing and tattooing
- Travelling
- Sick day rules
- Hyperglycaemia
- Hypoglycaemia
- Exercise
- Insulin pumps
- Emotional wellbeing
- Leaving home

#### Transition leaflet (locality based):

- Redditch
- Worcester
- Kidderminster

During transition young people and their carers are provided with the following information:

- Young Person's Information What's the difference between the Paediatric and the Adult Diabetes Service?
- Parent Information Transition to adult diabetes service: what's it all about?
- Parent Information Encouraging independence in your son or daughter
- Young Person's Information Negotiating independence
- Young Person's Information Transition to adult diabetes service: what's it all about?

These leaflets have been shared and agreed with the adult diabetes team. Also, a video on transition involving young adults describing their concerns and experiences has been produced and is on the Trust's website.

Digibete is also available as an extra learning resource for our CYP/their carers, enabling them to stay up to date by receiving National updates and allowing the diabetes team to communicate directly with our



patient population. We also use Digibete to send out our quarterly newsletter which includes updates from the team, 'top tips' for improving control, information from the Parents Support Group and upcoming events advertised. Other sources of support include:

- The Worcestershire Facebook group parent led, all families have information on the West Midlands Paediatric Diabetes Network Facebook group for additional peer support.
- Parents Support Group some parents, along with support from the MDT, run a parent support group and offer 3 or 4 meetings a year. Parents are encouraged to set the agenda and topics for discussion for these meetings.
- The West Midlands Paediatric Diabetes Network also run meetings (educational and support) for local families which we advertise on their behalf.

Funding permitted, extra-curricular activities take place to help improve the self-esteem of CYP, to encourage peer support as well as providing additional support to their parents. These also have an educational brief although in a more informal setting which is often beneficial in the learning process. This includes:

- An annual activity residential weekend for 8- to 13-year-olds
- An annual teenage activity day for 11- to 17-year-olds
- A Christmas party
- A family day and BBQ

# **Individualised Objectives (M20)**

Every child and young person has agreed individualised objectives, which are reviewed and updated regularly. These include:

- life-style goals which include explanations about the benefits of exercise, the effects of exercise
  on blood glucose levels and about strategies for avoiding hypo- or hyperglycaemia during or
  after physical activity
- advice about smoking avoidance/cessation both for the CYP and their carers this is monitored on Twinkle
- target blood glucose levels and how to achieve these through insulin adjustment
- therapeutic interventions (pharmacological and non-pharmacological)
- self-care
- individualised healthy meal planning for the child/young person and their family including carbohydrate counting and co-morbidities that effect dietary management
- education and education plan covering, as a minimum, school attended, medication details, what to do in an emergency whilst in school, giving/supervision of injections by school staff and arrangements for liaison with the school
- early warning signs of problems, especially high and low blood glucose levels, and what to do if these occur
- who to contact for advice and their contact details (emergency contact advice is included at the end of clinic letters)
- planned review date and how to access a review more quickly, if necessary this information is included in the patient's clinic letter

During MDT clinic appointments the CYP is encouraged to develop their own individualised objectives based on the items listed above. The objectives are reviewed at the next clinic appointment, if not before by the MDT.



# **Diabetes Self-Management Education (M21)**

The aim of the Worcestershire Paediatric Diabetes team is to provide consistent high quality, age and maturity appropriate education from the time of diagnosis and throughout the diabetes journey of the CYP and family so that the individual can eventually manage their diabetes with confidence and fit it into their individual lives. The MDT ensures that each CYP has an individualised structured education programme that is updated on a continuous basis.

Structured education is commenced at diagnosis using a checklist proforma within the nursing notes documentation. This is consolidated with written information provided in an A4 folder for families called 'Living with Diabetes'. This folder can also act as the CYP's personal care record and families are encouraged to keep copies of subsequent clinic letters in this folder. Following discharge from Riverbank Ward, the PDSN'S have daily telephone contact (except at weekends) with the CYP and their carers for the first 2 weeks following diagnosis as well as delivering two face-to-face educational sessions to cover information on relevant topics given in the Living with Diabetes folder. This folder also contains information on the local Diabetes team and how and who to contact for advice. CYP and their carers also have two face-to-face meetings with a paediatric diabetes dietitian in the first fortnight following diagnosis. Carbohydrate counting is taught with the aim of having CYP and/or their carers doing Level 3 carbohydrate counting within 2 weeks of diagnosis taking into consideration the individual learning abilities of families. As mentioned in 'Patient Information and Support', Deapp is being implemented to help with the structured educational process of the newly diagnosed diabetic.

All patients receive at least eight additional contacts annually e.g. telephone contacts, school visits, emails, troubleshooting advice, support etc. The PDSN's document these on an Excel spreadsheet and they are also entered into Twinkle and PAS.

Ongoing education and topics covered are documented using 'Goals of Diabetes'. This is an age banded, quality assured, educational and goal setting tool that identifies education given and assesses self-management in relation to the personal preferences, emotional wellbeing and age and maturity of the CYP. It is begun within 3 months of diagnosis and is held in the nursing notes but can be completed by any member of the team (who has had the appropriate training) at the multidisciplinary clinic or at any other contact such as during a home visit by the PDSN's. This is an especially useful tool for those young people who choose not to attend group education and it is reviewed annually.

There is a structured educational event held every year for all ages and treatment options. Dietetics offer educational events based on current need including carbohydrate counting and an update to the population with coeliac disease.

A group structured education programme is also offered for insulin pump starts. Pre-pump start there is a detailed appointment with the dietitian to ensure carbohydrate counting skills are up to date. The pump start session (for 2-8 patients at a time) consists of a full day when starting the insulin pump and one further 4-hour follow-up session. The aim of these sessions is for the CYP and their carers to get the most out of using their insulin pump, and to encourage self-management in the titration and alteration of doses where possible. For existing pump patients, an update event is offered every 12-18 months.

A structured education programme for CYP starting on continuous blood glucose monitoring/hybrid closed loop system is also available, and training is provided on how to interpret and use the flash glucose monitoring Libre device.



		Date
Is the programme delivered by members of the CYPD MDT who have undertaken appropriate training in paediatric diabetes management and education?	Esther Anstey	N/A
Is there a structured, written curriculum?	Goals of Diabetes	Jul 2016
Is the programme adjusted to the age and developmental stage of the child/young person?	Yes, age bands include: 6–7-year-olds 8–9-year-olds 10–11-year-olds 12–13-year-olds 14–15-year-olds 16–18-year-olds	
Is the programme quality assured against the programme agreed across the Network?	Yes, nationally agreed programme	Jul 2016
Does the programme fulfil the requirements of NICE NG18 2015, NICE QS125 2016?	Yes	Jul 2016
Does the programme have a named core member of the CYPD MDT who is responsible for organising the diabetes self-management education programme on behalf of the CYPD MDT?	Esther Anstey	
Is the programme reviewed annually?	Yes, by Esther Anstey	

# Record of Care (M22)

At diagnosis all CYP and their carers are provided with an information folder. They are encouraged to keep this as a hand-held record of care received and file clinic letters which are written to the CYP and their carers (with their GP copied in).

### **Miscellaneous**

#### Patient experience measures and audit participation

Patient Reported Experience Measures (PREM) (including Patient/Carer Experience of Transition and Transfer) - results are presented and discussed at CYPD MDT meetings with action plans agreed and implemented.

National Paediatric Diabetes Audit (NPDA) – individual unit reports are reviewed and presented to the CYPDN, Countywide diabetes team and Paediatric department for discussion and a programme for improvement is agreed.



Results of the above are fed back to CYP and their families.

#### **Podiatry**

Podiatry services are accessed via referral by the Consultant or PDSN.

#### Social Services Support

Social care is accessed via Worcestershire County Council's Family Front Door service. PDSNs actively attend safeguarding meetings, looked after child meetings and multiagency meetings. There are also regular meetings held with the Trust's Named Nurse for Safeguarding to discuss challenging cases.

### **Implementation**

This policy is documenting current practice within the paediatric diabetes service and therefore is already being implemented.

#### Plan for implementation

Countywide paediatric meetings, Quality Improvement meeting, Diabetes Network meetings

#### Dissemination

To the Paediatric Diabetes team and associated services meeting CYP with diabetes

#### Training and awareness

The training needs of the medical staff are identified in their annual appraisals and addressed as necessary with appropriate support for study leave.

The training needs of the PDSN's are also identified annually and they are supported to attend educational meetings (ACDC, Nottingham Paediatric Diabetes Conference, pump training, etc.)

All staff will attend mandatory training (listed in Analysis Appendix A of the Trusts Mandatory Training Policy) which may include occasional, additional safeguarding training.

# Monitoring and compliance

#### **NPDA**

Data is submitted to the NPDA to assess performance, identify areas for improvement and benchmarking.

### Paediatric diabetes BPT

Data is also submitted to the ICB to demonstrate compliance with the BPT.

#### West Midlands Paediatric Diabetes Network audits

We also submit data to Network audits which have recently included a DKA audit.

#### **Policy Review**

The trust has a mechanism for automatic review of all guidelines - whereby the main author is reminded by email of the need to update a guideline that it due for review.



### References

Please see the administration page for the Diabetes and Endocrinology treatment pathway for all references.

#### **Supporting Documents**

Supporting Documents 1: Equality Impact Assessment Tool Supporting Documents 2: Financial Risk Assessment Tool

Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

		Yes/No	Comments
1.	Does the policy/guidance affect one group less or more favourably than another on the basis of:		
	Race	No	
	Ethnic origins (including gypsies and travellers)	No	
	Nationality	No	
	Gender	No	
	Culture	No	
	Religion or belief	No	
	Sexual orientation including lesbian, gay and bisexual people	No	
	Age	No	
2.	Is there any evidence that some groups are affected differently?	No	
3.	If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?	N/A	
4.	Is the impact of the policy/guidance likely to be negative?	No	
5.	If so can the impact be avoided?	N/A	
6.	What alternatives are there to achieving the policy/guidance without the impact?	None	
7.	Can we reduce the impact by taking different action?	No	

If you have identified a potential discriminatory impact of this key document, please refer it to Assistant Manager of Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact Assistant Manager of Human Resources.



### Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	Yes/No
1.	Does the implementation of this document require any additional Capital resources	No
2.	Does the implementation of this document require additional revenue	No
3.	Does the implementation of this document require additional manpower	No
4.	Does the implementation of this document release any manpower costs through a change in practice	No
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments:	No

If the response to any of the above is yes, please complete a business case and which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval



## **Appendices**



#### **Appendix 1 - Mission statement**

## Your Paediatric Diabetes Team



What you can expect from us: We will:

- Offer at least 4 clinic appointments per year with a Paediatric diabetes doctor, nurse & dietitian and to check your Hba1c
- Offer annual screening for complications including: blood tests for thyroid function and coeliac screen for all ages and cholesterol blood test, foot exam, urine for microalbuminuria and retinopathy screen (over 12 years)
- Offer psychological support for the child / young person and family when required
- The team will be available for extra support, advice, troubleshooting and checkups by e-mail, telephone and in clinic
- Offer occasional home visits when needed
- Offer an additional appointment with a dietitian once per year and as required
- Offer ongoing education tailored to the needs of the child / young person and their care providers including structured education events, teaching in schools, home and clinics. Some of this will be included in social activities for the child / young person and their families to enjoy
- We will support the young person through the transition to adult Diabetes Services

#### Our Aim:

To provide consistently high quality care to children & young people with diabetes, their families and care providers. We will offer support and education to enable the child / young person to become independent in managing their own diabetes by the time they reach adulthood.



What we expect from you as a parent/guardian or young person:

- To attend your 4 clinic appointments per year and have available your blood glucose diary and meter for review
- Where possible, to download pumps in advance of clinic appointments to enable a more thorough review and in-between clinics for further support and guidance
- To be proactive in reviewing blood glucose levels and adjusting insulin and to request support and advice when needed
- To participate in offered education to enhance skills for managing diabetes
- To use your diabetes service to gain the knowledge and skills to manage your diabetes independently



#### Appendix 2 - Paediatric Diabetes Countywide Meeting

#### **Terms of Reference**

#### 1.0 Name of Group

Paediatric Diabetes Countywide Meeting

#### 2.0 Terms of Reference

2.1 Agreed February 2024

#### 3.0 Purpose of Group

3.1 To ensure the provision of high-quality care by the paediatric diabetes team. To be assured that the correct systems are in place within the service to deliver safe and effective care with as high a level of patient and family satisfaction as possible.

#### 4.0 Membership

4.1 Consultant Paediatrician and Clinical Lead - Chair

Paediatric Diabetes Specialist Nurses

Consultant Paediatrician and Clinical Fellow

**Paediatric Dietitians** 

Clinical Psychologists

Paediatric Diabetes Administrator

Directorate Manager

Lead Consultant for Care of Adults with Diabetes

Trust Lead for point of care testing

Matron for Children's services

Named Nurse for Safeguarding

Secretarial Support

4.2 To be quorate the minimum of Chair or their deputy, one PDSN and three other member of the MDT need to be present.

#### 5.0 Accountability

5.1 The paediatric diabetes team is accountable to the Women and Children's Directorate via the Quality Improvement Meeting.

#### 6.0 Working Methods

6.1 The Paediatric Diabetes Countywide Meeting will review the following:



- a. Children and young peoples' admissions related to DKA,
   hypoglycaemia, re-stabilisation, conditions unrelated to the management of diabetes and those with newly diagnosed diabetes.
- b. Datix's (clinical incidents) and safeguarding issues.
- c. Policies, protocols and procedures to ensure they are up to date.
- d. Issues related to staffing within the team.
- e. Ongoing quality improvement projects and action plans
- f. Data for Young adults transferred to Adult diabetes care, their follow ups and admissions.
- g. Training and educational policy for paediatric ward staff.
- h. Compliance with service specification including Paediatric Diabetes BPT and the National Quality Improvement/Quality Assurance and National Peer Review Programmes.
- i. PREM and National Audit results.
- j. Information from the West Midlands Paediatric Diabetes Network meetings and WAHNHST governance meetings.
- 6.2 Meetings will be held every two months. Twice a year the meeting will be part of Paediatric Diabetes Away Days.

#### 7.0 Sharing of Information

- 7.1 Agendas and minutes are approved by the Lead Paediatric Diabetes Consultant and the Lead PDSN and are sent out by email within a week of the meeting.
- 7.2 Agendas and minutes will be stored in a shared folder on the M:Drive for all parties to refer to.
- 7.3 The Lead Paediatric Diabetes Consultant will provide feedback to the Quality Improvement Meeting.

#### 8.0 Review

8.1 Terms of Reference to be reviewed every two years.



# Appendix 3 - West Midlands Paediatric Diabetes Network agreed 24-hour advice service specifications

Here is the agreed statement regarding BCH Diabetes Clinical Cover for local diabetes services operational policies to facilitate peer review standards:

- All units must have local clinical cover for out of hours advice to non-diabetes specialist consultants for the care of diabetes, including support for insulin pump therapy issues and CGM.
- All non-diabetes specialists in the (local) Trust paediatric on call rota will be competent and have regular training in the management of diabetes emergencies including DKA, severe hypoglycaemia and managing diabetes during inter-current illnesses as well as care of the newly diagnosed with diabetes.
- Local guidelines for trouble shooting with CSII, CGM, DKA, hypoglycaemia and sick day rules and for the care of the well newly diagnosed are in place to support this.
- For patients with diabetes who are seriously unwell, in the unusual event of the local diabetes specialist being unavailable out of hours, and the local consultant paediatrician on call requiring medical advice, the Regional Endocrine on call service and / or KIDs service at Birmingham Children's hospital can be contacted for advice on a consultant-to-consultant basis.



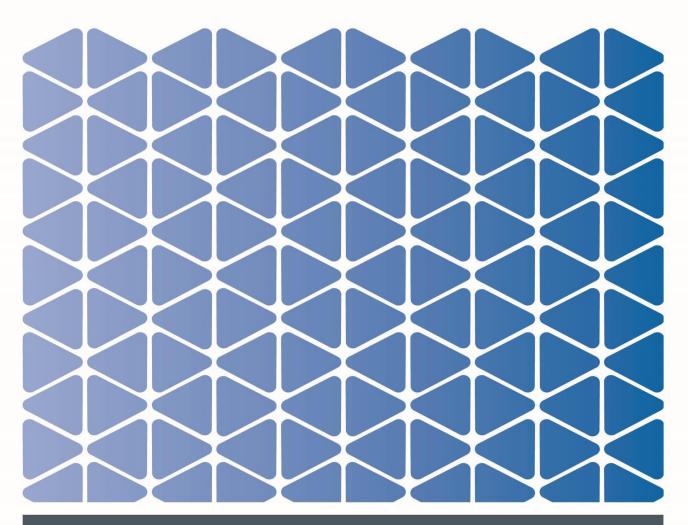
#### Appendix 4: Out-of-hours Advice Leaflet





### PATIENT INFORMATION

# Paediatric Diabetes – Out of Hours Emergency Contact and Other Information











During a normal working week (Monday – Friday 9am – 5pm) your usual diabetes nurse will be able to give advice should you experience any problems. Occasionally another Paediatric Diabetes Specialist Nurse (PDSN) in the County may be providing cover for your usual nurse. Contact numbers for the PDSN team are:

Esther Anstey/ Jane Francis – 07879 440181 Becki Walling – 07786 981146 Tracey Jones – 07436 037361 Lee-Ann Edwards - 07881 787239

Paediatric Ward - advice can also be obtained out of hours, weekends or bank holidays from Riverbank Ward, Worcester Royal Hospital Tel 01905 760588. Ask to speak to the Registrar.

#### **Insulin Pumps**

If you use an insulin pump chose the appropriate company below for advice:

#### Medtronic - 01923 205167

This is a 24hr helpline for technical problems with the pump or sensors (not for blood glucose or insulin dose related problems). You will only be charged for a local rate call even though the call goes to America.

#### Roche (Accu Chek) - 0800 731 2291

Advice can be obtained overnight and weekends or bank holidays, for problems with blood glucose levels, insulin doses and pump errors.

#### Omnipod- 0800 092 6787

24 hour advice can be obtained from a diabetes nurse.

#### **Blood Glucose Meters**

If you have a problem with your blood glucose meter please contact the relevant company below:

**Ascensia (Contour) – 0835 600 6030** Monday – Friday 8.00am-20.00pm **Abbott (Freestyle/Insulinx/Libre) – 0800 612 3006** Monday – Friday 8.00am-5.30pm **Roche (Expert/Mobile) 0800 858 8072** Monday – Friday 8.00am-6.00pm

#### Other information resources

Diabetes UK and JDRF (Juvenile Diabetes Research Foundation) are leading national charities in the UK which do a great deal of work to help people with diabetes; supporting them and helping them to understand and manage their condition, they raise large amounts of money which goes towards research. They also have key educational areas for your child's age group on their web site. Ask a member of your Diabetes team for further details. If you join Diabetes UK, Balance magazine or a magazine related to your age (Tadpole times, On The Level) will be sent to you every few months, which contains information on Diabetes, latest news and recipes. JDRF also have a wide range of support material including Rufus the Bear for younger children.

Diabetes UK offer a free year's subscription if your child has Diabetes and JDRF offer a free kids pack with Rufus the Bear. Both organisations also provide additional support material for schools. If you want to meet other people living with diabetes, to share and learn from each



other in a relaxed and fun environment? Then Diabetes UK's events are for you. They have events for children, adults and families. They also offer a "My Life" section on their web site for age related information on diabetes.

All the blood glucose meter companies have useful helplines and web sites with additional support materials some particularly relating to children and young people.

#### **Local Parents Group**

There is a local parent support group which has about 3-4 meetings a year. They have a Facebook group to help support local families. You can contact the group by searching on **Facebook for "Worcestershire Juvenile Diabetes Group**". If you have difficulties accessing this or wish to be put on the mailing list, contact your Diabetes Nurse who will ensure you are invited to join the group.

#### **West Midlands Paediatric Diabetes Network**

This is a local organisation where all the professionals involved can meet and network the best ways forward to improve their services. There is also a Facebook group that lets parents connect to families in the West Midlands.

Search on Facebook "West Midlands Paediatric Diabetes Network Parents Group"

#### **Useful websites**

Diabetes UK www.diabetes.org.uk JDRF www.JDRF.org.uk

Abbott www.freestylediabetes.co.uk

AccuChek www.accu-chek.co.uk Ascensia www.diabetes.ascensia.co.uk

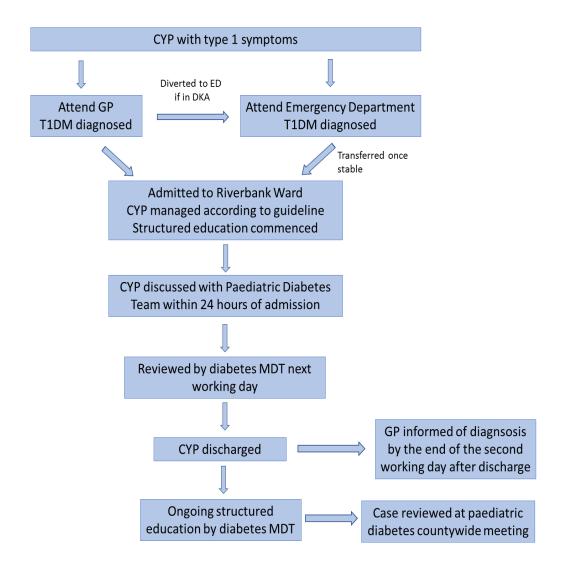
For teenagers www.teenagehealthfreak.org
For Parents and children www.Digibete.org
For sporty teenagers www.runsweet.com

For ID <u>www.medicalert.org.uk</u> <u>www.nextofkin.eu</u>



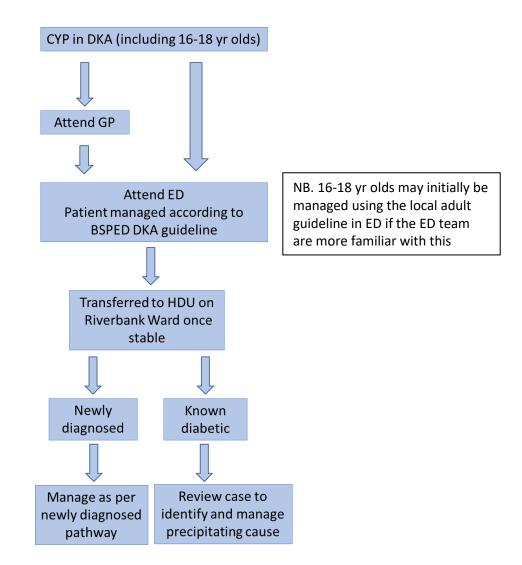
#### **Appendix 5 - Patient Pathways**

#### **Newly Diagnosed Pathway**



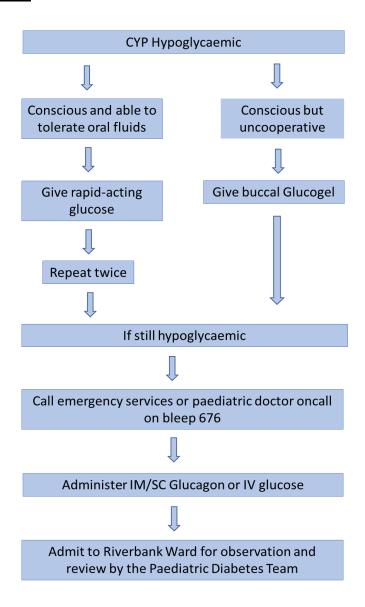


#### **DKA Pathway**





#### Hypoglycaemia Pathway





## **Appendix 6 - GP letter templates**



#### Patient demographics

Worcestershire
Acute Hospitals NHS Trust

Patient name:			
Hospital number:			
NHS number:			

Date of birth: Gender:

Patient address:

SP practice
SP name:
SP practice details:
SP practice identifier:

Location: Worcestershire Royal Hospital

#### Paediatrics Medicine Discharge Summary

· · · · · · · · · · · · · · · · · · ·		
Admission details		
Admission method:	Date of admission:	
Patient location: Worcestershire Royal Hospital		

Discharge details	
Discharging consultant:	Date of discharge: Time of discharge:
Ward: WRH River Bank Ward Paediatrics	Discharging specialty / department:
Discharge destination: Discharged home.	Discharge address:

Plan and requested actions				
Actions	When			
No follow up tests for this admission.				
For review at outpatient department at Worcester Royal Hospital in	6 weeks.			
Investigations and procedures requested				
Investigations requested:				

#### Diagnosis

Diagnosis	Code	Date	Туре	Status
Juvenile Onset Diabetes Type 1	E10.9		Primary	Confirmed

Procedures				
Procedure	Complications related to procedure?	Date		

#### **Clinical summary**

Management comprised of IV fluids, Initiation of insulin treatment. xxxxxxx is x years old and presented with ir thirst and some possible increased lethargy before bedtime, as well as a short duration of a headache. She ha polyuria. Urine Dipstix showed glycosuria and ketones. Her glucose on admission was 27.2 mmol/l with a norr 7.46, HC03 24.1. She was started on Novorapid 2.5units tds and Levemir 5 units nocte before bedtime.

Xxxxxxx has been reviewed by Dr West, the PDSN and dietitian. The Orchard team will provide additional sul discharge.

MRSA screening not performed. The patient had no health care associated infection during this admission.

Medication to take home and side effects discussed. Medicine last given on the ward: Novorapid at

#### Person completing record

Medical: Name & Grade: Nursing: Name & Grade: Date completed: Date completed:

1



#### Patient demographics

Patient name:

Hospital number: NHS number:

Date of birth: Gender:

Patient address:



Location: Worcestershire Royal Hospital

#### Paediatrics Medicine Discharge Summary

The venflon was removed. Resus training not applicable.

Please give insulin as prescribed and advised by doctors. If you are concerned please seek help through the appropriate ways e.g. diabetic nurse specialists (in hours), orchard community children's nurses or Riverbank Ward at Worcestershire Royal Hospital.

#### Investigations results:

No investigations to report.

#### **Medications and Medical Devices**

Prescribed by: Ward pharmacy check:

Pharmacy GP Advice:

#### Drugs on discharge:

Drug Name & Strength Comments	Form & Route	Dosage & Frequency	Qualifiers	Continue by GP or State Course	POD Qty	Ward Qty	Pharmacy Qty
INSULIN ASPART (Novorapid) 3mL CARTRIDGE Pre meals	S/C - Subcutaneous	2.5 units 3 times daily 8 hourly		Yes		TTO pack	Yes
INSULIN DETEMIR (Levemir) 3mL CARTRIDGE	S/C - Subcutaneous	5 units At night		Yes		TTO pack	Yes

#### Drug changes:

Medication	Started	Stopped	Dose Change	Reason for Change
INSULIN ASPART (Novorapid) 3mL CARTRIDGE	Х			Pre meals
INSULIN DETEMIR (Levemir) 3mL CARTRIDGE	X			

Allergies and adverse reactions
There are no drug allergies or sensitivities

Assessment scales

#### Person completing record

Medical: Name & Grade: Date completed: Nursing: Name & Grade: Date completed:



Patient demographics Patient name: Hospital number: NHS number: Date of birth: Gend Patient address:		Worcestershire Acute Hospitals NHS Trust				
Location: Worcestershire	Royal Hospital					
Paediatrics Medicine Dis	scharge Summary					
Information given	Information and advice given: Verbal information given to carer. Information leaflets given					
Legal information						
Advance decisions about treatment:						
<b>5</b>						
Distribution list		10. 100.500				
Patient	GP	Copy of GP EDS given to parents and Community Paeds.				

Person completing record

Medical: Name & Grade: Nursing: Name & Grade: Date completed: Date completed:









Paediatric Diabetes Specialist Nurses
Community Diabetes Specialist Nurses Office
Alexandra Hospital
Woodrow Drive
Redditch
Worcestershire
B98 7UB
paeddiabetes@nhs.net

Becki Walling 07786 981146 <a href="mailto:becki.walling@nhs.net">becki.walling@nhs.net</a> Lee-Ann Gayle 07881 787239 lee-ann.edwards@nhs.net

Date

GP address

Hospital No: NHS No:

Name:

D.O.B:

Address:

Dear GP,

Your above named patient has been diagnosed with Type 1 Diabetes. The Paediatric Diabetes Team will be providing regular support and guidance whilst the family are coming to terms with the diagnosis and learning about the care required, including carbohydrate counting to fully utilise this type of insulin regimen.

#### **Current Treatment:**

Tresiba insulin units

NovoRapid insulin pre breakfast units, pre-lunch units and pre-tea units Plus correction doses of NovoRapid as advised.

The patient has been discharged using the following insulin and equipment. I would be grateful if you could ensure these items are put on repeat prescription. There are some changes to the discharge letter requirements due to providing appropriate equipment for school staff to support medical needs.

Items in bold are required today.

- 1. Novopen Echo plus insulin pen device 1 x red and 1 x blue
- 2. Penfill 3ml cartridges of NovoRapid insulin



- 3. Penfill 3ml cartridges of Tresiba insulin
- 4. Caresens Pro blood glucose testing strips x 250 per month
- 5. Ketosens blood ketone testing strips x 10 per month
- 6. Caresens lancets
- 7. BD VIVA Needles 4 mm
- 8. Dextrogel (or other brand supplied) 1 box 3x25g tubes
- 9. GlucaGen Hypokit 1mg
- 10. Sharps Box 1L x2

Parents are made aware that I provide support Monday to Friday basis except bank holidays and that out of hours they can access Riverbank Children's ward at Worcester Hospital direct should they need advice or emergency care regarding Diabetes.

Please do not hesitate to contact me should you require any further information.

Yours sincerely

Becki Walling Lee-Ann Gayle Paediatric Diabetes Specialist Nurse



# Appendix 7 - Paediatric Diabetes Multidisciplinary Team (MDT) Home Visit Guideline

The PDSN's offer home visits to CYP and their carers particularly on diagnosis to help with adjustment to their diagnosis and aim to establish a good working relationship as well as offering a supportive and educational role. Home visits can be offered by all members of the multidisciplinary team (PDSN's, Dietitian, Psychologist) at any time when individual need is identified using the criteria below.

Home visits can be time consuming and are not always a cost-effective use of team resources. This guidance is to offer a structured approach to whom and when home visits should be considered. It is however a guide only and home visits can be useful for specific needs and should be at the discretion of the MDT and health professional involved.

Where possible, families/young people should be encouraged to attend a clinic for health care appointments.

#### Safety of Staff and lone working

All staff who are home visiting should be aware of the **Lone Worker Policy WHAT CG 511** and know how to keep themselves safe. Newly diagnosed patients are assessed on the ward and staff will highlight any concerns to the team before discharge. A risk assessment in the home will be completed at the first visit and recorded on Bluespier. The multidisciplinary team should communicate to each other any ongoing concerns surrounding visiting at home. All staff will keep a log in a diary/whiteboard at base of their intended visits and whereabouts and ensure colleagues and senior staff know where they are going.

#### MDT criteria for who may be considered for a home visit:

- Patients or their carers who have a disability, mental health issue or a medical condition that makes them less able to come to additional appointments.
- Patients from families where there are a number of siblings and childcare is not available, making it difficult for the family to attend additional appointments.
- Patients from families who have no access to own transport and are unable to come for an
  additional appointment on public transport or in a taxi (this can be particularly difficult in rural
  areas).
- Families who are identified as experiencing financial hardship.
- Any vulnerable young person/family where a clinic visit does not help with engagement.
- Regular non-attendance at clinic See DNA guideline WHAT-PAE-102.

#### School and nursery visits

- Patients living in boarding schools or other institutions may need to be considered for home visits to be able to provide education to a group of carers/catering company, if such a need is identified by the MDT.
- School or nursery visits by the dietitian should be performed in special circumstances if there is a need to address specific issues.
- It is routine for PDSN's to visit, educate and support medical needs in this environment.
- The psychologist or other member of the MDT may attend multi-agency meetings as necessary held
  in the school or other environment as required and occasionally may see a young person in school if
  a need is identified.