Clinical Guideline

NEWLY DIAGNOSED TYPE 1 DIABETES CARE PATHWAY FOR CHILDREN & YOUNG PEOPLE (UP TO 19TH BIRTHDAY)

SETTING	Acute medical areas
FOR STAFF	Medical and nursing staff
PATIENTS	Children and Young people (up to 19th birthday) with type 1 diabetes and their families

Local diabetes teams need to take on the responsibility of ensuring that any staff in their trust who are expected to use these guidelines are given training in how to use them.

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1. INTRODUCTION

Type 1 diabetes (T1DM), also known as insulin dependent diabetes is an autoimmune disease that permanently destroys beta cells in the pancreas, so that the body can no longer produce insulin. It is the most common form of diabetes in children and young people (CYP). The current estimate of prevalence of Type 1 diabetes in CYP under the age of 19 years in the UK is one per 430-530.

T1DM symptoms should be treated immediately, as without treatment with insulin it is not compatible with life.

Symptoms include:

- **History of polyuria/polydipsia**
- **Feeling tired**
- **Losing weight**
- Skin infections
- Genital itchiness

4 T's
- Thirsty
- Toilet
- Thinner
- Tired

2. SCOPE

This care pathway is to be used by all staff in clinical areas caring for newly diagnosed Children & Young Person (CYP) with T1DM up to their 19th birthday. The care pathway will then be used by the CYP Diabetes team to continue care after discharge.

CYP Diabetes Team: includes specialist CYP nurses, paediatric consultants, paediatric dietitians & paediatric clinical psychologists

3. PURPOSE

- To plan, facilitate and promote a safe, seamless commencement of insulin therapy
- To provide continuity and consistency of care, minimising duplication and gaps in care to CYP and families
- To ensure CYP and their families are given the appropriate education to enable them to continue management and become experts in their own diabetes management once discharged. The aim is a good quality of life and to reach their full potential.
- To minimise the risk of severe hypoglycaemia and diabetic ketoacidosis (DKA).
- To minimise prescribing errors.
- To increase CYP/ families' satisfaction with the care and advice given.

4. DEFINITIONS

World Health Organisation (WHO) diagnostic criteria for diabetes based on blood glucose measurement and presence of symptoms:

1. **Random plasma glucose concentration of equal to or greater than 11.1mmol/L**
   Random is defined as any time of day without regard to time since last meal.

   OR

2. **Fasting plasma glucose of equal to or greater than 7.0mmol/L**
   Fasting is defined as no caloric intake for at least 8 hours.

Note: ***Oral Glucose Tolerance Test (OGTT) is not required for diagnosis of TIDM.*** It is generally required for evaluation of suspected type 2 diabetes, monogenic diabetes or cystic fibrosis related diabetes.

5. CAPILLARY BLOOD KETONES (CBK)

Capillary blood ketone measurement provides an accurate indicator of Diabetic Ketoacidosis (DKA). The blood ketone meters used in hospital, measures the blood ketone - β-hydroxybutyrate - directly. New patients are given a blood ketone meter for home use.

INTERPRETATION OF BLOOD KETONE MEASUREMENT	
Blood Ketones	Significance
Less than or equal to 0.6mmol/L	**Normal**
0.7 – 1.5mmol/L	**May require additional quick-acting insulin immediately. Inform doctor. Recheck blood glucose & blood ketones 2 hourly.**
1.6 – 2.9mmol/L	**AT RISK OF DKA** **Will require additional quick-acting insulin IMMEDIATELY (see page 8). Recheck blood glucose & blood ketones 2 hourly.**
Greater than or equal to 3.0mmol/L	**ASSESS FOR POSSIBLE DKA AS PER DKA GUIDELINE** ▪ **Up to 18th birthday use:** The Integrated Care Pathway for Children & Young People with Diabetic Ketoacidosis (up to their 18th birthday ▪ **18th birthday onwards use**: The Management of Diabetic Ketoacidosis (DKA) in Adults (i.e. aged over 18 years) – CGSG 119

6. DUTIES

Acute area staff (medical & nursing staff): print the care pathway from the Knowledge Centre (KC) and begin working through the pathway.
CYP Diabetes Team: support the acute area staff and continue working through the pathway with the CYP/family on discharge.

7. KEY MESSAGE

Families, children and young people with diabetes benefit greatly from a good start to diabetes care with confident, clear, positive messages, support and advice. The Association of Children's Diabetes Clinicians (ACDC) recommends frequent contact with the families to help manage the changing requirements of diabetes in its early phases. The contacts may be in clinic, at home visits or by telephone.

NEWLY DIAGNOSED TYPE 1 DIABETES CARE PATHWAY FOR CHILDREN & YOUNG PEOPLE (UP TO 19TH BIRTHDAY)

Name: *(Use sticker)*	**NHS no.**	DATE:
Address:	**Hospital no.**	TIME:
DOB:	GP:	CONSULTANT:

Seen in (department):	Admitted to:

INITIAL RAPID ASSESSMENT

On presentation assess:

- **A**irway
- **B**reathing
- **C**irculation
- **D**isability

Weight: ……. Kg

Temp: ……

Pulse: ……

Are any of the following present?	✓	×
blood pH < 7.30 or Bicarbonate <18mmol/L		
Blood glucose > 11.1mmol/L		
Blood ketones > 3mmol/L		
And / or dehydration > 5%		

If so, consider DKA and IMMEDIATELY discuss with consultant on call.

DKA YES ☐ NO ☐

N.B. If CYP is in Diabetic keto-acidosis use **The Integrated Care Pathway for Children & Young People with Diabetic Ketoacidosis (up to their 18th birthday)** or **The Management of Diabetic Ketoacidosis (DKA) in Adults (i.e. aged over 18 years)** policy first (print from KC).

DIAGNOSIS of T1DM without DKA

DIAGNOSIS MUST BE UNEQUIVOCAL: Doctor to explain the diagnosis to CYP and family

a) History of polyuria/polydipsia, +/- weight loss.
b) Glycosuria.
c) Random Capillary Blood Glucose (CBG) greater than or equal to 11.1mmol/L or fasting CBG greater than or equal to 7mmol/L

Explain confirmation of the diagnosis will be made once the Laboratory blood glucose level is available.

Capillary Blood Glucose: …… mmol/L

Capillary Blood Ketones: …… mmol/L

NB: If capillary blood ketones (CBK) greater than 1.5mmol/L go straight to CBK guidance on page 8

*Print Care Pathway and use it in conjunction with the Starter Pack (see Pg. 11)

Staff details to be recorded in full below, then initials may be used within the document.

NAME:	SIGNATURE:	TIME	DATE	Initials

ALL children presenting with newly diagnosed diabetes require the blood tests • below

BLOODS to take:	(✓)	Date	Initial	BLOODS to take:	(✓)	Date	Initial
• Thyroid function				•GAD antibodies			
• Thyroid antibodies				•Islet cell antibodies			
• HbA1c				•Coeliac screen			
• Lab glucose				•FBC, U&E, LFT			
Blood culture if febrile				Urine culture if febrile			
Amylase if severe abdominal pain				CRP if febrile			
Further infection screen dependent on clinical assessment							

PLEASE NOTE: items with * denotes education and training that **must be** provided to the child/young person & family before discharge.

***On diagnosis, CYP MUST be discussed with a senior member of the Children & Young Persons (C&YP) diabetes team within 24 hours of presentation. It is essential this information is documented.**

Date:	Time:	Discussed with:	Name/signature/designation:

Each child to be seen by a member of the Diabetes Team on the next working day (Monday – Friday).

Date:	Time:	Seen by:	Name/signature/designation:

USEFUL CONTACTS:

CYP Diabetes Team office: **Tel: 01438 288311 or X8311 (QE2)** **Fax: 01438 288399 (QE2)**

CYP Diabetes Out of Hours Service: **Tel: 01438 285000 (PARENT HELPLINE)**

(5pm to 8am Monday - Friday 24 hours weekends and bank holidays)

Adult Diabetes Specialist Nurses (for young people aged 16yrs up to 19th birthday):
Monday-Friday 9-4pm bleep 1016
Saturday, Sunday & Bank holidays 08.30-12pm bleep 1016

Ensure that diabetes training is commenced and documented. Key information and practical skills that CYP with type 1 diabetes need to know before they leave hospital are:

- **How to do CBG (capillary blood glucose)**
- **How to administer insulin**
- **Awareness of hypoglycaemia and management if CBG near normal range before discharge**

As soon as possible order supplies from pharmacy – see page 10

ADMISSION

Discuss with a member of the Diabetes Team (MDT). It may be necessary to admit for education and support, as some families need time to adjust to the diagnosis even if not ketoacidotic.

Children under 6 months of age must be admitted. Those under 6 weeks should be transferred to a tertiary centre.

Patients above 16 years of age are likely to be admitted to adult wards and managed by the adult medical/diabetes teams in collaboration with the CYP Diabetes Team (see KC Guideline CP218- Regarding the Care of 16-18year old Patients with Diabetes admitted to East & North Herts NHS Trust).

*INSULIN

All CYP should be commenced on Multiple Daily Injection (MDI) insulin regimen at diagnosis. Children on MDI insulin regimen take a once daily basal insulin in the evening (before bed) and rapid acting insulin before carbohydrate containing food.

Rapid acting insulin analogue

Insulin NovoRapid®

The first injection is the most important in the child's life. Make it sensitive and stress free.

Long acting basal insulin analogue

Insulin Lantus® (glargine)

Give a **Total Daily Dose (TDD)** **of 0.75units/Kg**. For children less than 5 years, consider 0.5 units/Kg total daily dose.

CYP under 8yrs require: 0.5 unit Novopen Echo (red) for insulin Novorapid & 0.5 unit JuniorStar pen (blue) for insulin Lantus.

CYP over 8yrs require: 0.5 unit Novopen Echo (red) for insulin Novorapid & 1 unit Lantus Solostar pen for insulin Lantus

TABLE 1

MULTIPLE DAILY INJECTION REGIMEN:	**EXAMPLE:**
Insulin LANTUS (Glargine) **Once a day in the evening before bed** **40% TDD** **Insulin NOVORAPID** **60% TDD divided by 3 meal times** **(to be given before the meal)**	**Weight = 40Kg x 0.75 units/Kg: TDD = 30 units** **Therefore:** **Insulin LANTUS (Glargine): 12 units** **Insulin NOVORAPID: 6 units / 6 units / 6 units** **TDD = 30 units**

ALL children newly diagnosed with type 1 diabetes need to be treated with insulin regardless of the time of day of diagnosis.

If the time of diagnosis does not fit with the insulin timings above i.e. it is not a meal time or bedtime then give Insulin NOVORAPID 0.1 unit/Kg as a STAT dose and commence basal bolus regimen at the first mealtime.

ALWAYS prescribe STAT dose of Insulin NOVORAPID on the STAT section of the drug chart.

It is important to use **Insulin NOVORAPID** as this will reduce CBG and 'switch off' blood ketone production.

*Demonstrate to parents and CYP how to use their insulin pen and perform an **injection;** encourage them to practise.	**(✓)**	**Date**	**Initial**

*CAPILLARY BLOOD GLUCOSE (CBG) MONITORING

The CYP and family will have a home blood glucose meter **in their starter pack.** It is important they become confident in its use. **Ensure they know the meter & finger pricking device are single person use only.**

NB. If the CYP is an in-patient, any insulin dose adjustments must be made using the blood glucose reading obtained from the Trust calibrated (point of care) blood glucose meter (please ensure patients use their own finger pricker device).

• Demonstrate to CYP and family how to use their meter as soon as possible; once they are confident, encourage them to use meter • Check CBG levels at least 5x/day including pre-meals, after school and pre-child/ parents bedtime. Do not do CBG levels during the night unless the CYP feels unwell • Record all results in home monitoring diary and on the prescription chart. Explain to CYP and family how to fill out diary	**(✓)**	**Date**	**Initial**

If CBG is less than 4mmol/L refer to the Guideline for Management of Hypoglycaemia (on Trust KC) Hypo guideline.

*CAPILLARY BLOOD KETONE (CBK) MONITORING

• Check CBK on admission: if CBK < 1.6mmol/L repeat at next CBG check. • CBK greater than or equal to 1.6mmol/L give Insulin NOVORAPID without delay. If this coincides with a mealtime use the calculations in TABLE 1, Pg 7. Repeat CBK after 2 hour. If not, give Insulin NOVORAPID dose at 10% of calculated TDD (TABLE 2, Pg 9). Repeat CBK after 2 hour. • If CBK continue to be greater than or equal to 1.6mmol/L repeat STAT dose of Insulin NOVORAPID as above leaving a minimum of 2 hours between Insulin NOVORAPID doses. Report static or increasing CBK levels to doctors for advice re: further management. **NB: CBK levels should reduce once insulin therapy has commenced.** • Once CBK less than1.6mmol/L repeat CBK with next CBG to avoid multiple finger-prick checks. • Once CBK levels are 0.6mmol/L or below no further CBK testing required unless the CYP deteriorates(NB: CBK of greater than 0.6mmol/L should not delay discharge in a well-child with reducing CBG) • The CYP Diabetes nurses will educate family re: use of CBK testing meter in starter pack after discharge.	**(✓)**	**Date**	**Initial**

*MANAGEMENT OF ELEVATED CBG LEVELS DURING FIRST FEW DAYS AFTER DIAGNOSIS

The blood glucose levels will 'run high' for the first few days. There is no need to keep correcting with extra doses of insulin NOVORAPID in between regular doses unless CBG **is >20mmol/L.** Constantly giving small amounts of insulin NOVORAPID in a newly diagnosed child who is well, is unnecessary.

TABLE 2

If CBG is greater than 20mmol/L give 10% of TDD of insulin as a correction dose using Insulin NOVORAPID.

EXAMPLE:

Child weight = 40Kg TDD of 30units (if starting on 0.75 units/Kg/day) 10% = 3 unit correction dose of Insulin NOVORAPID.

- **Correction dose can be given between meals or at night or dose added to mealtime insulin dose if due.**
- **Correction doses should have a minimum 2 hour gap between doses and check CBG 2 hours after a correction dose is given.**

Always prescribe correction dose of Insulin NOVORAPID on the 'ONCE ONLY PRESCRIPTION' section of the drug chart (ensure UNITS is written in full)

During next few days insulin doses will be adjusted by the family with the support of the CYP diabetes team.

*DIET

	(✓)	Date	Initial
In the first couple of weeks following diagnosis children will often eat more than they would normally. This is usual and will settle. Sweets and chocolates are not banned from the diet; small amounts may be eaten after a meal. Explain to parents: • CYP requires a **healthy, balanced and age appropriate diet.** • Take carbohydrate with each meal. Snacks are not essential but in the first few weeks are expected due to increased hunger. • CYP requires **sugar free drinks**. Diet fizzy drinks or squash with no added sugar are acceptable. • Some ideas for snacks: small packet of crisps, 2 savoury crackers/rice cakes, cheese/sliced meat, small cereal bar, a plain biscuit, a handful of fruit or 2 breadsticks. • **Snacks over 10g carbohydrate may require an additional Insulin NOVORAPID injection.**			

EDUCATION

*Encourage CYP and parents to begin reading the Education Booklet in the Starter Pack. Ask them to write down questions they have.

	(✓)	Date	Initial
• *Aim of treatment is to maintain BG levels pre-meal **4 – 7mmol/L** and post meal **5- 9mmol/L** as often as possible. For those intending to drive BG must be above **5mmol/L** before driving. • *Explain to parents and CYP **about hypoglycaemia (CBG level <4mmol/L),** its causes and how to treat, at an appropriate time. This is most important for those with CBG levels near normal range during admission. Please refer to hypoglycaemia information in **Education Booklet in starter pack.** • CYP Diabetes Team – blood ketone testing • CYP Diabetes Team - glucagon training 2-3months after initial diagnosis • CYP Diabetes Team - hyperglycaemia and sick day rules • CYP Diabetes Team - exercise • CYP Diabetes Team - relevance of HbA1c			

REFERRALS & MULTI-DISCIPLINARY TEAM

	(✓)	Date	Initial
• Refer to CYP Diabetes Dietitian at diagnosis to commence carbohydrate (CHO) counting. • CYP Diabetes team to complete GP letter regarding diagnosis and repeat prescription requirements. GP letter must be faxed to GP by the end of the second working day after discharge. • CYP Diabetes Team to make OPA for **4-6 weeks** in the appropriate clinic.			

SUPPLIES FROM PHARMACY

***MDI Regimen (under 8 years)**	***MDI Regimen (over 8 years)**
• **Insulin NOVORAPID 3ml PENFIL CARTRIDGES X 5** *Provide 0.5 unit **Novopen Echo(red)** insulin pen from diabetes cupboard on Bramble Suite* • **Insulin LANTUS (GLARGINE) 3ml PENFIL CARTRIDGES x 5** *Provide 0.5 unit **JuniorSTAR (blue)** insulin pen from diabetes cupboard on Bramble Suite*	• **Insulin NOVORAPID 3ml PENFIL CARTRIDGES X 5** *Provide 0.5 unit **Novopen Echo(red)** insulin pen from diabetes cupboard on Bramble Suite* • **Insulin LANTUS SOLOSTAR (GLARGINE) X 2 pens**

PLUS:

- BD Microfine Needles (4mm) x 1 box of 100
- Glucogel x 1 box

SUPPLIES HAVE BEEN ORDERED FROM PHARMACY	**(✓)**	**Date**	**Initial**

DISCHARGE

	(✓)	Date	Initial
• *Discharge weight _____ Kg • *Provide the CYP and family with **24-hour telephone contact numbers** card and explain who and how to contact for support. Check postal address and family telephone contact numbers – document them. • *Admitting Medical Team to review available blood results before discharge & inform CYP Diabetes Team of any pending results. • *If CYP Diabetes Team have not seen the patient before discharge and taken the red folder please FAX front sheet & care pathway (i.e. this document) to the CYP Diabetes Team office (01438 288399) and send the red folder home with the family. • CYP Diabetes Team to review pending/diagnostic blood results. • CYP Diabetes Team to inform Paediatric Psychologist of Diagnosis.			

It may be necessary for CYP to return to **CAU or ED** department if they require additional support with injections and/or CBG monitoring until CYP Diabetes Team becomes available. The CYP Diabetes Team will continue care after discharge.

FOLLOW UP

- Family will be contacted by The CYP Diabetes Team following discharge. Home and school visits will be arranged as appropriate.
- All children with T1DM should have access to 24 hours telephone advice.
- All school aged children should have a school care plan in place either before or soon after return to school (the school care plan will be completed jointly by the family, school staff, C&YP Diabetes Team & School Health Team).

CONTENTS OF DIABETES STARTER PACK (RUCKSACK) FOR FAMILY: cupboard on Bramble

• Accu-chek Aviva meter • Accu-chek Fastclix lancet drums x 2 boxes • Accu-chek Aviva Test strips x 1 box of 50 strips • Control solution x 1 box • Optium Blood Ketone Test meter & 2 strips • CYP Diabetes Education Booklet Rucksack for under 10 years has a teddy.	• Blood glucose diary • Small sharps bin • Red diabetes community folder • Business card with telephone numbers for CYP Diabetes Team & CYP Diabetes Out of Hours Service (this is in the back of the red folder)

Appendix 1 (each unit to adapt to their own educational needs)

Education topics to be covered at Diagnosis and the first month following diagnosis

TOPIC	DATE	Name	Signature	Designation
What is Diabetes?				
Causes				
Symptoms				
Explanation of Honeymoon Period				
Insulin				
Different types of insulin, action & duration of action				
Dosages				
Use of correction doses				
Storage				
Leaflets				
Injections				
Technique				
Sites/rotation				
Use of pen/pump device				
Timing of insulin injections				
Disposal of sharps				
Capillary Blood Glucose Monitoring (CBGM)				
Why, how and when to test				
How often & when				
Target range				
When & how to seek advice				
Ketone Testing				
Why, how and when to test				
Interpretation of results and actions to take				
When & how to seek advice				
Hypoglycaemia				
What is hypoglycaemia				
Causes/symptoms/prevention				
Management including use of glucose tablets, Glucagon etc.				
Dietary Advice				
Healthy eating				
Carbohydrate awareness/counting				
Exercise Management				
When to CBG monitor				
How to manage carbohydrates & insulin				
Illness Management				
Sick day rules and Diabetic Ketoacidosis prevention				
24hr Telephone contact numbers				
School				
School care plan				
Equipment for school including hypoglycaemia treatment				
Identifying a place to CBG monitor & inject				
Prescriptions				
When & how to obtain repeat prescription items				

Identification				
Medic alert / diabetes card				
Disability Living allowance				
Where to obtain form & where to obtain help to complete e.g. DUK				
Support Groups/ Services				
DUK, JDRF, East of England face book group				

MONITORING COMPLIANCE

- Audit of care pathway
- Monitor any adverse incidents as per Trust policy

REFERENCES

Association of Children's Diabetes Clinicians (2012) Care of the well child newly diagnosed with Type 1 Diabetes Mellitus. Agwu J, Moudiotis C, Matyka K et al.

National Collaborating Centre for Women and Children's Health (2004, 2009 & 2011) Type 1 Diabetes diagnosis and management of type 1 diabetes in children and young people.

National Institute for Health and Care Excellence (2015) Diabetes (type 1 and type 2) in children and young people: diagnosis and management (ng 18)