NHS
The Dudley Group
NHS Foundation Trust

Diabetes in five minutes – a survival guide for going home

Paediatric Diabetes Department

Parent/Carer Information Leaflet

Introduction

This leaflet is for parents of children who have been diagnosed as having type 1 diabetes. It has information on what you can expect from the Paediatric Diabetes Specialist Team, key information to help you in your first few days at home, what happens at clinic appointments and what to do about school.

Who are the Paediatric Diabetes Specialist Team

Our small team are based at Russells Hall Hospital. The team consists of:

- Consultant paediatricians - Dr Petkar, Dr Puttha
- Lead paediatric diabetes specialist nurse – Joanne Elford
- Paediatric diabetes specialist nurses - Rachel Ellis, Sam Northern
- Paediatric diabetes specialist dietitian – Hannah McOnie
- Paediatric diabetes psychologist - Vacant Post
- Paediatric diabetes administrator - Jill Danks

What happens now?

Being given a diagnosis of type 1 diabetes for your child can be overwhelming. It can be a difficult time for you but be reassured that you are not alone. We will visit you frequently during your stay in hospital and provide you with support and information. We will help you learn the skills that you need for when you go home.

When you go home, we will be in regular contact with you by visiting you, telephone calls, emails and texts. You will also have access to 24 hour telephone advice from the Children's Ward. You can contact them on 01384 244271.

What can I expect from the team?

- Daily visits in hospital on weekdays when your child is first diagnosed
- A home visit the day you leave hospital or the next day
- Three home visits in the first two weeks
- Two education sessions in the first month, plus a continuing programme of structured learning
- Another home visit about six weeks after you leave hospital
- We will arrange a school care plan meeting as soon as it is practical after you leave hospital. We will also offer annual training for your child's school
- Clinic appointments, initially after two weeks, then every three months
- We offer you a home visit and diet review every year

What do I need to do?

- Be available on the Children's Ward so the team can teach you what you need to know for when you are at home
- Attend education sessions
- Attend clinic appointments. Bring along your blood glucose and blood ketone meters, and blood glucose diary
- Update us if any of your contact details change
- Ring the Paediatric Diabetes Team at least once a week in the first month to let us know how it is going
- Come to the school care plan meeting

Key messages

It is not your fault – type 1 diabetes is not caused by anything your child has had to eat or drink; or anything else you have done. It is caused by an autoimmune response in the body which means the immune system attacks healthy body tissue by mistake. In this case, it attacks the cells in the pancreas. The damaged pancreas is then unable to produce insulin. So glucose cannot be moved out of the bloodstream and into your child's cells.

It is very different to type 2 diabetes - the team will explain this in more detail.

It is for life – type 1 diabetes is a life-long condition. There is no cure currently although lots of research is being carried out.

Your child can lead a fulfilling life – having type 1 diabetes should not stop your child doing anything they want in life. The only career options that are ruled out are the Armed Forces and some driving jobs. The team will provide support on how to manage exercise, school trips, including residential trips and family holidays.

Brief reminders to help in the first few days at home

If you are in any doubt about anything, call for advice.

Blood glucose testing

- You will need to check your child's blood glucose levels before meals, two hours after meals and before bed. Also if they are feeling unwell.
- Always wash your hands before testing or use approved wipes only, such as Dia Wipes or Accu-Chek sterile cleansing hand wipes, which are available to buy online.
- Write down all the readings in the blood glucose diary we give you and use highlighters to identify low and high blood glucose levels.
- Aim for blood glucose levels between 4 to 7mmol/L.
- Low/hypo is a blood glucose level of less than 4mmol/L (see section on 'Low blood glucose levels (hypos)' for more information on this).
- High/hyper is a blood glucose level of above 7mmol/L. If it is a mealtime, see your correction chart. If the blood glucose level is above 14mmol/L, you will need to test your child's ketones (see section on 'High blood glucose levels (hypers)' for more information on this).
- **Before bed test:** if your child's blood glucose level is less than 7mmol/L before bed, you will need to give your child a 15g carbohydrate snack without extra insulin. This may be reviewed with the paediatric diabetes team at a later date.

Insulin

- Long acting insulin (Levemir, Lantus or Degludec) should be given at the same time each evening. It should keep your child's blood glucose levels steady throughout the next 24 hours.
- Fast acting insulin (NovoRapid) should be given 10 to 15 minutes before meals and large snacks.
- Before you inject insulin, point the needle upwards and do an air shot of two units or more if needed, until you see the insulin bubble or stream. This is to ensure the pen is working before you inject.
- Insulin should be kept in the pen at room temperature for up to 28 days.
- Spare cartridges should be kept in the fridge until the expiry date.
- Do not allow insulin to freeze, for example against the back of fridge or a freezer pack, or to get too hot (above 30°C). Insulin is a protein and it will not work if it is too hot or too cold.
- Try to do your injections in different spots to avoid injection lumps. We will show you how to do this.

Eating

- Make sure your child eats regularly – three meals a day. There should be some carbohydrate at each meal.
- Try to make sure your child fills up at mealtimes rather than with snacks in between meals. However, initially we suggest that one 10g to 15g snack of fruit in between meals is allowed.
- There is no special diabetic diet. No foods are forbidden. Diet recommendations should be the same as for any other child or young person of the same age.
- All drinks should be sugar free unless it is fruit juice or milk included with a meal.
- There is no need to buy special diabetic products. They are expensive, unnecessary and can have undesirable effects.
- Our dietitian will spend time teaching you how to count carbohydrates in the food your child is eating so you can adjust insulin doses.

Sharps disposal (see leaflet in your pack for more information)

- Put all sharps into the sharps bin provided.
- The sharps bins will be on prescription from your GP. When they are full, return them to your GP or your local pharmacy.
- Keep the bins out of the reach of children.

High blood glucose levels (hypers)

- If your blood glucose is above 7mmol/L at mealtimes, see your child's correction chart. The only time you will not need to use a correction dose of insulin is if the high blood glucose level follows a hypo/low blood glucose level reading.
- If your child's blood glucose level is above 14mmol/L, check for blood ketones. If ketones show as less than 0.6mmol/L, this is safe (LO on the display means less than 0.1mmol/L).

  If the ketones are 0.6mmol/L or more, call immediately for advice as you will need extra insulin.
- If your child is unwell or being sick, ring the Children's Ward as you may need to come in.

Contact numbers

Call the paediatric diabetes team on 01384 456111 ext. 3148/3149/3150 (9am to 5pm, Monday to Friday excluding bank holidays).

Out of these hours, call the Children's Ward on 01384 244271.

Low blood glucose levels (hypos)

- A low or hypo is a blood glucose level of less than 4mmol/L – “4 is the floor”.

- Give your child 5-15g of fast acting glucose. The team will advise you on an amount of glucose depending on your individual child’s age/weight. Examples of fast acting glucose:
    - a mini can of full sugar cola or lemonade
    - GlucoTabs
    - Lucozade Energy drink

If your child is unable to take these as they are too confused, give them a whole tube of Glucogel (as long as they can swallow)

- Wait 15 minutes, wash your hands and retest your child’s glucose level.

- If it is still below 4mmol/L, give them another 5-15g of fast acting glucose as above. Wait 15 minutes, wash your hands and retest your child’s glucose level. Repeat until the glucose level is above 4mmol/L

- When your child’s glucose level is back above 4mmol/L, give 5-15g of a slow acting carbohydrate snack such as two plain biscuits or small piece of fruit.

A hypo can very occasionally cause unconsciousness or a seizure. If this happens, do not put anything in your child’s mouth. Call 999. Lie them on their side and give them a glucagon injection if you have one and feel able to.

INDIVIDUAL HYPO TREATMENT AMOUNT ADVISED:

________________________________ g of fast acting glucose

What about school?

We want your child to return to school and their normal routine as soon as possible. Before this can happen, a meeting will need to take place between the Paediatric Diabetes Team, school staff, your child and you. At this meeting, a healthcare plan will be negotiated. This will include training and educating staff on how to safely provide care in school.

What are medical alert tags and bracelets?

These are a useful safety measure for people who have diabetes and are becoming more independent. They come as watches, bracelets and pendants. You can buy them from the following weblinks:

www.laurenshope.com http://www.medicalert.org.uk/

Disability Living Allowance

The Disability Living Allowance (DLA) is a government benefit that you may be eligible to receive for your child. Please ring 0800 121 4600 to request a DLA form to be sent to you, or you can download and print the form yourself.

https://www.gov.uk/disability-living-allowance-children

Advice on how to fill it in appropriately is available at:

https://www.diabetes.org.uk/How_we_help/Advocacy/Disability_Living_Allowance/

We can complete the section that needs to be filled in by a medical professional.

What happens at clinic appointments?

We will offer you clinic appointments at Russells Hall Hospital for your child every three months. You and your child will see a doctor, diabetes nurse and a dietitian. At this appointment we will:

- weigh and measure your child
- check their blood pressure
- do a finger prick blood test

If you cannot make the appointment, please call the outpatient booking team on 01384 244164. However, if your appointment is within the next seven days, please call your consultant's secretary.

Please bring your blood glucose and blood ketone meters and diaries to these appointments.

What is an HbA1c test?

The HbA1c test is carried out three times a year using a finger prick test and once a year using a blood test. It measures the amount of glucose that is being carried by the red blood cells in the body. The higher the levels of glucose in the blood over time, the more glucose will be stuck to the red blood cells. This will result in a higher HbA1c measurement.

On average, a red blood cell lives 120 days. Therefore, the HbA1c level reflects the average blood glucose over the previous two to three months. This gives a longer-term trend of blood glucose levels over a period of time. The results can indicate whether the measures you are taking to control your child's diabetes are working.

New guidelines recommend aiming for a HbA1c level of less than 48mmols, without frequent hypos. This will reduce the risk of developing complications that can result from high levels of blood glucose. However, any reduction in HbA1c levels will help reduce the risk of developing complications.

In the long term, having high HbA1c levels increases the risk of developing complications of diabetes, such as eye disease, kidney disease, heart disease, strokes or impotence.

How can I help my child achieve their HbA1c target?

1. Try to keep your child's blood glucose level between 4 and 7mmol/L all the time.
2. Test your child's blood glucose five times a day.
3. Be very accurate when you are counting carbohydrates.
4. If your child's pre-meal blood glucose is more than 7 mmol/L, always add a correction dose to the meal time insulin.

5. If your child is on a pump, always put the blood glucose reading through the bolus wizard and use the recommended insulin dose.
6. Review your child's blood glucose diary at least every two weeks and adjust your insulin, if necessary.
7. Aim for your child to be active for at least 60 minutes every day.

What will be checked at the annual diabetes review?

Your child will have a blood test to check for cholesterol, thyroid disease and coeliac disease.

Additionally, for children over 12 years of age we will:

- Take a urine sample to screen for diabetic kidney disease
- Check your child has had diabetic eye screening
- Take your child's blood pressure
- Carry out a foot examination

Can I find out more?

You can find out more from:

Dudley Parent Support Group – TOPS (Type One Parent Support)

Contact Colin Noone 07837 376371

Juvenile Diabetes Research Foundation (JFRF)

www.jdrf.org

Diabetes UK (DUK)

www.diabetes.org.uk

Contact numbers

If you need help or you have queries, please contact:

Diabetes nurses and dietitian on 01384 456111 ext. 3148/3149/3150 (9am to 5pm, Monday to Friday excluding Bank Holidays)

Out of these hours, contact:

The Children's Ward, Russells Hall Hospital on 01384 244271 (24 hours a day, seven days a week)

Dr Petkar's (Secretary) – 01384 244367 (9am to 5pm, Monday to Friday)

The outpatient booking team on 01384 244164

All children and young people with type 1 diabetes have open access to the Children's Ward. This means you can call 24 hours a day for advice and, if needed, your child can be seen on the ward by the nursing and medical team.

This leaflet can be downloaded or printed from:

http://dgft.nhs.uk/services-and-wards/paediatrics-and-neonatology/

If you have any feedback on this patient information leaflet, please email dgft.patient.information@nhs.net

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

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