

K: Future Health

1. Introduction:

Lots of young people and their families have asked us for information on the possible long term impact of diabetes on your health or long-term complications which may occur in people with diabetes. We have tried to summarise these briefly below but please discuss these with the diabetes team. We have tried to be open and honest but also explain that working with the diabetes team to aim for blood glucose levels between 4 and 10 mol/L will **considerably** reduce the risk of these occurring.

At the time of your diagnosis, your parents may have searched the internet and have read all about these problems and will be worried. The Diabetes team is here to help to minimise this risk. Please discuss it with the team - it is really important to understand how you can reduce this risk to very low levels by keeping your blood glucose in the target range where possible from the beginning.

2. Background:

The body is designed to keep glucose levels in the blood within a very narrow margin (4-7mmol/L). The only hormone which lowers glucose levels is insulin. As insulin is no longer produced by the pancreas in type 1 diabetes, you have to try to match the insulin dose with the carbohydrate containing food you eat instead as well as having your basal insulin. If glucose levels are running high for a long time or there are large swings in blood glucose, it can irritate and damage the blood vessels, particularly small vessels as seen in the eye and kidney. They can bleed and small clots can form.

A study in the United States (DCCT) showed very clearly that maintaining blood glucose levels in target range for most of the time really reduced the risk of all complications and this effect lasted for many years. It is therefore really important to try to do this from diagnosis and then maintain it throughout. This can be a challenge but is possible using intensive insulin regimens (multiple daily insulin and/or pumps).

You may hear or read about some experts in diabetes talking about your body's 'metabolic memory'. What they mean is '*what your average blood glucose levels are like over the period you have had diabetes*'. The HbA1c test is a marker of glucose levels; the nearer that is to 48mmol/mol or 6.5% without lots of hypoglycaemia the more benefit for your health, whether you have had diabetes for 2 years, 20 years or beyond. Even if you have a period of higher HbA1c, it is worth improving to reduce your risks of longer-term problems.

Although it is better to keep blood glucose within the target range as much as you can as soon as possible after diagnosis, it is **never too late** to do this. This will always help to improve the situation and reduce the risk of complications. Look at the 'Top Tips' listing ideas which have been shown to help with this. If you have found

something which has helped, please email us so that we can discuss adding it to the list.

3. Nephropathy (kidneys)

One of the first signs of problems occurring in the kidney is the leakage of an excess amount of protein into the urine. Your diabetes team will check your urine for this once per year. If it is positive, the test will be repeated using a sample of urine collected as soon as you wake up in the morning when you have rested.

Another important sign of a kidney problem is a rise in your blood pressure. This should be checked at clinic and if it is significantly high (particularly if it is associated with the 'protein' leak), then medication will be required (ACE inhibitors).



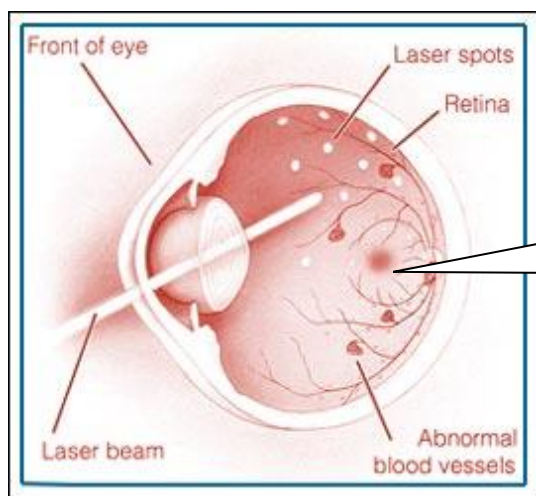
The kidney filters your blood to get rid of waste; if it stops doing this, you may need dialysis or a transplant.

To minimise the risk of these problems occurring it is important to

- Keep blood glucose control in the target range as much as possible
- Not to take up smoking- as it is known that smoking increases the risk considerably.
- Try and maintain a healthy weight for your height.

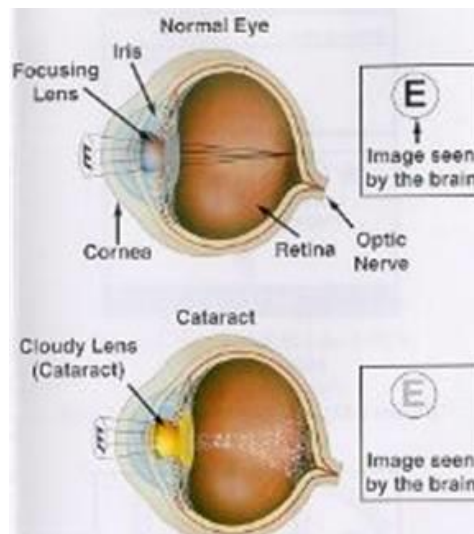
4. Retinopathy (eyes)

The small blood vessels at the back of the eye are particularly susceptible to damage from high blood glucose levels and large swings in blood glucose. Over time, this can lead to leakage of blood into the back of the eye (retina) and damage your ability to see. This is particularly serious if it occurs in the part of the eye associated with fine vision (macula).



Very fine blood vessels with 'bruises' associated with leakage of blood into the retina.

The lens of the eye can also be affected by high glucose levels leading to cataracts. This leads to a blurring of your vision and may require surgery.



To minimise the risk and to stop further problems if any are detected, it is important to:

- Maintain blood glucose in target range as much as possible, reducing it slowly if it has been high for a while. Please discuss this with your diabetes team.
- Avoid smoking.
- If recognised, it can be treated by using a laser but it is better to try and avoid the complication if at all possible.

1. Sexual Health

At the time of diagnosis this may appear to be one of the least important things on your mind. As you reach adult life the ability for normal sexual relationships becomes increasingly important. To minimise the risk of complications occurring, it is important to try to keep blood glucose in target range as much as possible from diagnosis. The problems that can occur include:

- In females, high glucose levels can be damaging in pregnancy. If you are planning to have children it is very important to discuss this with your diabetes team early on. You will need to keep blood glucose in target range and try and keep maintain this throughout pregnancy, but importantly follow advice before conceiving (getting pregnant) to minimise the risk to your baby. We have a specialist pre-conception clinic for women with diabetes. By doing this, you can have a healthy pregnancy and have a healthy baby. If you suspect you are pregnant, please let us know immediately so that you can have a test, be given appropriate advice and be referred to the specialist antenatal clinic if appropriate.
- In males, high blood glucose levels may over time be associated with difficulty achieving an erection and can affect the sex life of males and females with diabetes. Prevention is the best way of ensuring a healthy sex life but there are

treatments available if problems do occur. Please discuss this with your diabetes team if you have any questions.

2. Neuropathy (nerves)

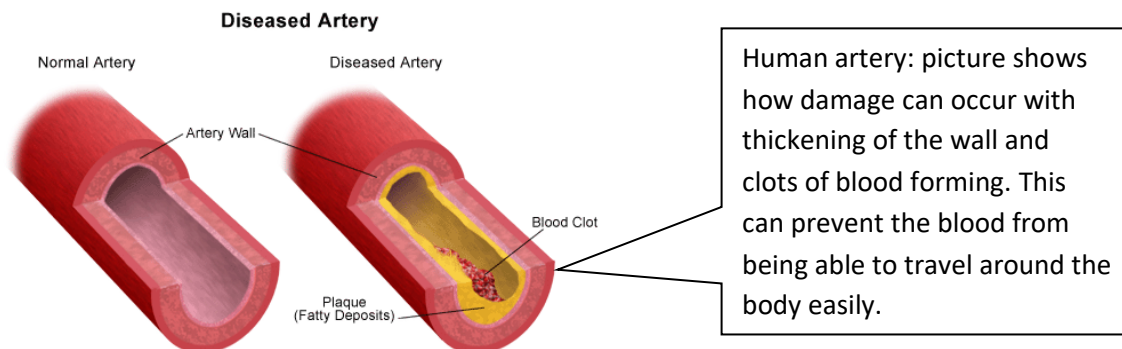
Problems associated with the nerve supply to your body (similar to the electric supply to your house) are rarely recognised in childhood but can start to appear very slowly. There are two areas which can be affected:

- The long nerves to your legs and arms can lose the ability to feel ‘touch and sensation’. This can make it difficult to feel and pick up small objects and you could tread on a sharp object such as a stone or piece of glass without noticing.
- The nerves to your stomach can be affected, making it unable to empty properly leading to a feeling of sickness, pain and at its worst, frequent vomiting. This can also affect blood glucose after meals

As with all long term complications, minimising the risk relies on trying to keep blood glucose levels in the target range. The diabetes team are here to support you and your family to help with this.

3. Blood vessels

The large blood vessels in your body can collect fat and ‘fur up’ like a kettle, this narrows your blood vessels and makes you more susceptible to heart damage. This is important to **everyone whether they have diabetes or not** and the risk can be reduced enormously if you:



- Avoid smoking at all costs and make every effort to stop if you have started (Try and not be exposed to a smoky environment). There are lots of services available with stopping smoking so please let us know if you would like help with this.
- Make healthy food choices including your 5 fruit and vegetables each day.
- Aim to keep blood glucose levels in the target range.
- Try and be active for 60 minutes per day. See sections G1 and G2 about physical activity and exercise.

10 TOP TIPS FOR GLUCOSE MANAGEMENT

We encourage regular review of your glucose patterns between clinics and would like to support you to develop skills and confidence to make changes to insulin doses. If you are not sure what to change, or would like some help, please call the diabetes team rather than wait until your next appointment. Here are our top 10 tips to help you.

1. Always give insulin **before** food. 15 minutes before food is best.
2. Keep a blood glucose (BG) diary, create your own spreadsheet or regularly download your meter/pump. Look at this with your child and problem solve together. BG level target range is 3.9 - 7mmol/L. 5mmol/L is ideal.
3. Look at the average BG on the meter over a 14 day period, checking BG at least 5 times a day. An average BG of less than 8mmol/L will help your HbA1c be close to target.
4. Look for frequency of hypos - 2 or 3 mild hypos per week are generally to be expected, more than this needs insulin reduction. Can your child recognise their hypo?
5. If there are **high BG levels in the mornings** (more than 7mmol/L for 3 days or more in the week), check you are in target before bed. If so, increase long acting insulin. Always optimise basal insulin first before changing mealtime insulin.
6. How to increase basal insulin (e.g. Levemir/Glargine/Tresiba)
 - If the dose is less than 10 units of long acting insulin, increase by $\frac{1}{2}$ unit at a time
 - If the dose is 10-20 units of long acting insulin, increase by 1 unit at a time
 - If the dose is more than 20 units, increase by 2 units
7. If there are **high BG levels before bed**, change the evening meal ratio in the expert meter or pump (e.g. if 1 unit per 10g carbs, change to 1 unit per 8g carbs. This will give you approximately $\frac{1}{2}$ - 1 extra unit per meal.
8. If there are **high BG levels** for 3 or more days in a week **before a particular meal**, increase the insulin ratio for the meal eaten before the high levels (e.g. if the BG level is high at lunchtime, increase the breakfast dose). Check this change has been effective by checking 2 hours after meal for a few days.
9. Always give the usual correction dose if BG levels are more than 8mmol/L before a meal and consider at other times if needed.
10. Always consider lumpy injection sites (lipos), if BG levels are variable.

K2: Research

The Leeds Children and Young People's Diabetes team try very hard to ensure you are always offered the most up to date treatment. We have dedicated staff working on a range of exciting research studies for children and young people with diabetes and their families.

If we think you or a family member might be suitable for one of our studies, we will contact you with more information. We also advertise the studies we are involved with in our quarterly newsletter and on the research notice board in our waiting room. You can also ask to speak to one of our research nurses for more information.

Taking part in a study is entirely voluntary and you will be given age appropriate information and have the opportunity to discuss the study with a member of our research team before agreeing to participate.

If you decide you don't want to take part or wish to leave a study early, your clinical care will continue and will not be negatively affected. You will never be pressured to take part in a study.

Taking part in studies can potentially offer you the opportunity to try new ways of managing diabetes, help us learn more about different types of diabetes and help new treatments become available in the future. However, we recognise that taking part in a study can be a big commitment and are always happy to discuss how taking part in research might affect you.

As well as seeing people for research in the diabetes clinic at St James' hospital, we also have a Children's Clinical Research Facility, C-Floor, Clarendon Wing that we sometimes use for longer visits.



K3: Useful web addresses

General

DigiBete www.digibete.org

Diabetes UK www.diabetes.org.uk/

Juvenile Diabetes Research Foundation www.jdrf.org.uk/

Medical alert wearables

Medi tag alert bracelets www.medi-tag.co.uk

Universal medical ID www.identifyYourself.com

Medical tags www.medicaltags.co.uk

The ID band company www.theidbandco.com

General

Lenny the lion teaching site: www.lenny-diabetes.com/

Change for life-health advice. www.nhs.uk/Change4Life

Insulin pump accessories

www.funkypumpers.com

www.diabete-ezy.com