

J: Future Health

J1: Information for Parents and Carers - Emotional Well-being and the Clinical Psychology service in the Diabetes Team

After diagnosis

As a parent or guardian, it can be a huge shock when your child receives a diagnosis of diabetes. Getting a diagnosis can be traumatic as children can sometimes be quite unwell by the time they receive the right medical help. This can happen for a number of reasons and it can be hard for parents not to feel guilty or blame themselves. Although this is a common response for parents and usually goes away over time, it is important to remember to be kind to yourself at this time.

It is normal to feel anxious or worried about your child's diabetes in the beginning. Sometimes it is hard to achieve a balance between managing diabetes (and helping your child to stay safe), and their desire for freedom and increasing independence.

Diabetes can bring additional responsibility and disruption to family life and it is common to have emotional reactions to diabetes. You may notice changes in your child's behaviour or mood, or may struggle to encourage your child to manage their diabetes well.

What does a Clinical Psychologist do?

Despite your best efforts to help your child or to manage your feelings, sometimes things just don't seem to improve. Although we all have "ups and downs", sometimes it is more difficult to cope with things that at other times would not bother us. At these times, it can be useful to talk to someone trained to help with emotional or behavioural distress and it may be helpful to arrange a meeting with one of the Clinical Psychologists to see if we can help. The type of support that could be offered depends on your needs and Clinical Psychologists can help with a wide range of difficulties relating to having diabetes, including...

- Emotional support for parents. For example, if feelings of guilt or sadness after diagnosis carry on longer than six months or start to interfere with family life.
- If you find that things are not moving forward and feel "stuck" in relation to diabetes.
- Arguments and relationship problems caused by diabetes at home
- If you are worried about your child's behaviour or mood. For example, worries about weight and body image or feeling sad or down.
- If you are worried about your child's learning at school.
- Stress around living with diabetes

- Fear of hypoglycaemia or anxiety about having injections or medical examinations
- Difficulties managing the treatment regime

Clinical Psychologists are not medical doctors so they will not change your child's treatment or prescribe medication. However, if you feel that your child's treatment isn't working well, the Psychologist can help to communicate this with your doctor or nurse.

Emotional well-being and the team

Once a year, all families are asked to complete some questionnaires to help the team work together with you to address any concerns and build good emotional health. This will normally be done with your child's named nurse and also includes some questions for parents as we are aware that parents also need support at times.

What happens during my sessions with a Clinical Psychologist?

During your first appointment, the Clinical Psychologist will meet with you and your child together as a family. However, if you prefer, the psychologist can work with your child or family members independently and adults-only support is available for parents. We will keep a summary of our conversation together, although this information will remain confidential and will not be shared or given out to anyone who is not concerned with you or your child professionally without permission. However, all members of staff have responsibilities to protect children from harm and are legally bound to inform other professionals if a child is thought to be at risk. Under these circumstances, the Psychologist would discuss this with you first.

Who will you see?

Clinical Psychologists can work closely with the Paediatric Diabetes Team and have experience of working with children and young people with diabetes, as well as their families. Sometimes it might be easier for you to meet with people that could offer you support who are nearer to where you live but the clinic should be able to help you with this.

Sometimes, you may be seen by another member of the Clinical team or by a member of staff in a position of Clinical Training.

How long will you see the Clinical Psychologist for?

This will depend on what is discussed and decided with the Psychologist when you meet. Some people have just one session with a Clinical Psychologist, whereas others may have many more. We can work with you on your own or with your family. We can decide what might be most helpful in the first meeting.

The Psychologist will try to give you an idea of how many sessions you may need, but often this depends on your goals and progress made. It is sometimes the case that the psychologist may advise a referral to different services if this is felt more appropriate but you will always be kept informed.

What to do if you want to see a Clinical Psychologist?

If you feel that your child or family would benefit from seeing the Psychologist, please mention it to one of the nurses or doctors involved in your care. They will then contact us with a brief summary of the difficulties you are experiencing. Sometimes it may be decided that Clinical Health psychology is not the best service to meet your child's needs and if this is the case you may be referred or directed to an alternative service with your consent.

The Department of Clinical and Health Psychology will then contact you either by letter or telephone to arrange an appointment time.

J2: Information leaflet for Children and young people (7 + years) - A Guide to Clinical Psychologists in the Diabetes Team

Introduction

Living with diabetes can be hard at times, and most people struggle with it at some point.

It is normal to feel fed up and frustrated with Diabetes, but sometimes these feelings grow stronger and people can feel that they need extra help. A Clinical Psychologist can help you and your family to talk about these feelings and work out a way to make things easier.

What can a Clinical Psychologist help me with?

Clinical Psychologists have helped other children with:

- Worries about needles and injections
- Feeling very down about living with Diabetes
- Worries about going hypo
- Difficult feelings about food and weight
- Worries about managing your diabetes in school
- Feeling very angry about Diabetes (which might be causing stress at home)
- ...and lots more!

Clinical Psychologists don't give medication or change your treatment, but if you or your family think your treatment isn't right for you, the Psychologist can talk to your doctor or nurse for you.

What will happen when I see the Clinical Psychologist?

When you come for the first time, the Clinical Psychologist will talk with you and your parents together to find out what you would like help with. If you come more than once, it is sometimes useful to see the Psychologist on your own, but only if you want to. Sometimes only your parents may see the Psychologist.

How long will I see the Clinical Psychologist for?

The amount of times you see the psychologist will depend on if you want to talk to them and if the psychologist thinks you need to see them again. Some people come just one or two times, and other people come for many more sessions.

J3: The importance of control in preventing long term effects of diabetes:

1. **Introduction:**

Lots of young people have asked us for information on the long-term complications of diabetes. We have tried to summarise these briefly below but it is better to take the opportunity to discuss these with the diabetes team. We have tried to be open and honest but also explain that by working with the diabetes team and aiming for good control you will **considerably** reduce the risk of these occurring.

2. **Background:**

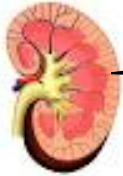
The body is designed to keep glucose levels in the blood within a very narrow margin (4-7mmol/l). The only hormone which lowers glucose levels is insulin. As you are unable to make insulin in type 1 diabetes, you have to try to match the injected insulin dose with the carbohydrate containing food you eat instead. If glucose levels are running high for a long time, 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 good control of blood glucose levels really reduced the risk of all complications and this effect lasted for many years. It is therefore really important to try and get good control from diagnosis and then maintain it throughout. This is tough but is possible using intensive insulin regimens (multiple daily insulin and/or pumps).

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 test 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 fails you need dialysis or a transplant.

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

- Keep blood glucose control as good 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. 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).

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 detected it is important to:

- Maintain good control of diabetes - 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

4. 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 then it is important to try maintaining good control 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 obtain good control and try and keep good control throughout pregnancy, but importantly follow advice before conceiving (getting pregnant) to minimise the risk to your baby. By doing this, you can have a healthy pregnancy and have a healthy baby. If you suspect you are pregnant, do discuss with your doctor and diabetes team immediately.
- In males, poor control may over time be associated with difficulty achieving an erection and in having a normal sex life. Although there are potential treatments for this it is better to prevent this in the first place. Do discuss with your diabetes team.

5. 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 and at its worst, frequent vomiting.

As with all long term complications, minimising the risk relies on trying to obtain good control and maintaining it. Use your diabetes team to help with this.

6. 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).
- Eat healthily including your 5 fruit and vegetables each day.
- If you have diabetes, to aim for good control.
- Try and be active for 60 minutes per day.

7. Your body's memory (metabolic memory)

You may hear or read about some experts in diabetes talking about your body's 'metabolic memory'. What they mean is '*what your average diabetes control is like*

over the period you have had diabetes'. The HbA1c test is a marker of glucose control; the nearer that is to 48mmol/mol or 6.5% without lots of hypoglycaemia the better, whether you have had diabetes for 2 or 20 years. It also tells you that even if you have a period of bad control, it is worth improving.

Although it is better to obtain good control as soon as possible after diagnosis it is **never too late** to get good control as this will always help improve the situation and reduce risk of complications. Look at the 'Top Tips' leaflet listing ideas which have been shown to give good control. If you have found something which has helped please email us so that we can add it to the list or discuss on the forum.

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 minimise this risk. Do discuss it with the Team - it is really important to understand how you can reduce this risk to very low levels if you work at it now.

J4: Top Tips-some ideas to think about which will help with your diabetes

Listed below are ideas which have been shown to help improve diabetes control. These ideas have been collected from the diabetes team, parents and children with diabetes and from articles about diabetes. Try and introduce 1 or 2 at a time and see how it helps. Improving control will make you feel better, be more confident and positive about your diabetes. Tick the box if you are doing it.

Ideas around testing and injecting:

1. Do rotate your injection sites every day. Injecting in the same site will lead to lipos, hypos, swinging blood glucose levels and poor control (see blood glucose testing).
2. Always remember to give your bolus insulin with food and drink containing carbohydrates. If you forget, ask about a device you can add to your pen which tells you when you last had insulin. On pumps look at your memory.
3. Inject insulin **before** food, if possible 10-15 minutes before. This requires a bit of planning, but if you can do this for your main meals it is a very good start.
4. Test your blood glucose before each main meal and at bedtime as a minimum. This allows you to correct high levels. (Use glucose tracker to look at your results if uncertain). The best results are achieved by testing more than 4 times per day.
5. Give insulin with snacks unless treating a hypo. You will be surprised how high your glucose level may go even if you have a small snack (see Snack attack for ideas for food without the need for insulin).

6. Although you may be rushing it is important to have some breakfast even if it is only a fruit drink or piece of toast with insulin. If you starve for long periods your body produces ketones and your insulin will not work so well.
7. If you are on multiple daily injections try not to forget your long acting insulin: link it to something you do every day such as cleaning your teeth.

Ideas around food

1. Make sure you know your correct insulin to carbohydrate ratio for each meal. If you are uncertain, consider a test meal or discuss with your Diabetes Team (see test meal).
2. Don't guess your insulin dose, try and work out the carbohydrate content of the food and then calculate the dose.
3. Consider trying a meter which helps you calculate your dose or, if on a pump, make sure you use the bolus calculator.
4. Work around your favourite meals first and get the dose right for these. Do this by testing your glucose before the meal, have your insulin and meal and then test 2-4 hours later. The glucose level 2-4 hours after food should be no more than 2 mmol/l above or below the pre meal dose. If it is high, have the meal again and give an extra unit and see if this is better. (see favourite foods)
5. If you are uncertain about how much you want to eat then give a dose at the beginning of the meal but top up with more insulin as soon as you know you want to eat more e.g. extra potatoes, extra slice of pizza, a pudding etc
6. Many snacks can increase your glucose level quite a lot and require insulin - do give insulin with snacks.
7. For big meals, those containing more than 80 grams of CHO, particularly if it is food where the glucose is in the form of starch or the food contains quite a lot of fat, it is sometimes necessary to split your bolus and give 50% at the beginning and the rest half way through. Those on the pump can give a dual wave bolus or extended bolus.

Ideas around lifestyle

1. Discuss diabetes with a close friend and ask them to help, e.g. blood glucose checks, reminders, listening to concerns and helping to find solutions.
2. Plan a little in advance for new events e.g. holidays, exams, job interview and think how to make sure you are at your best and well controlled so that you can enjoy it (holidays, not exams!!). Seek advice from the Diabetes Team.
3. If you are going out with friends, make sure you have your diabetes equipment (have a small bag you can carry them in), hypo treatment and some wearable ID stating you have Type 1 Diabetes (e.g. wristband/information card/engraved jewellery)