

PATIENT INFORMATION

Dealing with worries about diabetes:

a leaflet for parents or carers of children with a diagnosis of diabetes

Newly diagnosed?

I'm struggling to cope.

It is really important that, as well as having people to support your son/daughter, you have a network of people to support you. This might be your partner, family, friends, the diabetes team or other parents. It is natural to feel out of your depth at the beginning with all the information coming your way. Talk to someone about how you feel, and try and take a little time out to do something relaxing for yourself too.

I find it hard to see my son/daughter suffer.

This is a totally natural parental reaction. Your child will begin to get used to the routines, blood testing and injecting, but try and put some time aside every so often to talk to them about diabetes and how it feels for them. It can help to find support and information from the sites listed overleaf, both for yourself and for your child.

It is hard to see my child becoming distressed by needles/injections.

Understandably children may at first be really wary of their diabetes regimen. It can help to involve your child in deciding where and how to test and have injections, including where they would like to sit and whether they want to look (if you are injecting). Little rewards like sticker charts (depending on their age) could initially help too. Distractions could possibly take their mind off their injections. Younger children may find blowing bubbles helps, whilst other children might prefer listening to music or watching TV. What can be helpful is unique to each young person and you could ask them if they have any similar ideas which they feel may help them. If these strategies don't work, you can always speak to your diabetes team.

Supporting my son/daughter

My child is upset that they cannot have sweets like everyone else.

Regardless of diabetes, it can be helpful to remind young people that having sweets all of the time is not a good idea for anyone. It is fine for people (including children with diabetes) to have sweets or chocolate occasionally as part of a healthy balanced diet. It is also important for children to feel that they have some control and similar choices to their friends/siblings. If your child is carbohydrate counting, the diabetes team can help you to learn and understand how much insulin may be needed if he/she has a sweet treat following a meal.

My son/daughter is not looking after their diabetes as well as they could.

This can be difficult when you see that your son or daughter is not checking their bloods and/or not injecting as often as they should. It could be that they do not realise what they should be doing, or are simply 'fed up' with diabetes. It is important not to seem like you are blaming your child: this may affect your relationship and won't make them change their behaviour. It might help to sit with them and encourage them to explain how they are feeling. If this is becoming very difficult, speak to your diabetes team about how we as a team can support you all. They might recommend a referral to the psychologist who could explore their difficulties and talk through possible coping strategies with your child.

I'm worried that I am ignoring my other child(ren).

Following diagnosis, this can quite easily happen. It may help to think together about when you could all spend time together and when you could have alone time with each of them too, e.g. swimming lesson, helping with homework etc. Talking to siblings about the diagnosis and what it entails can help them to have deeper understanding too.

School

I am worried that school may not take care of my son/daughter like I can.

Many schools now have experience of supporting children with diabetes. The diabetes nurses and dietitians will go into schools to offer education and support for staff and to lead writing up a plan that they can refer to. If your school has a SENCO, it could be helpful to meet with him/her to discuss your child's needs, finding out what experience they have and whether you need to involve the diabetes team. Lots of useful information for schools can be found on the Diabetes UK website.

I am concerned that the school are not doing enough to support my son/daughter.

The school have a duty to support your child under the Equality Act 2010 and Sept 2014 Government Guidelines. Unwillingness to help can often come from being afraid of doing the wrong thing. Please talk to your diabetes team about this if you have concerns. It might be that a discussion or visit with the diabetes team could help them.

Activities, days out and sleepovers

I am worried about my son/daughter going on trips away/having sleepovers.

Having a diagnosis of diabetes should not stop your child engaging in activities that other children do, like sleepovers, days out and activity holidays. However, they may require some preparation, such as talking through and then devising a plan of your child's regimen with the adult responsible (e.g. parent at the sleepover, or the school/group leader taking children out). This will help to make sure that they are aware of what they need to do, and what your child needs to do. If necessary, you can ask your diabetes team to help. For a first school/club trip you could ask if you could go along to help as some parents do, for your own peace of mind and to support and inform staff for future trips.

What do the Clinical Psychologists do?

The Clinical Psychologists can work with you, your child, or the family as a whole, to help you/family find ways of coping with the diagnosis of diabetes as well as providing a space to talk about feelings and worries associated with the diagnosis.

The diabetes team can refer you to the Clinical Psychologists if you all think this would be helpful. You would then meet with him/her once or twice first to talk about how you are all coping at the moment, and then together decide whether more psychology input could help.

For more information

Please contact your diabetes team 01803 655579. The team are there to support you as you and your family learn about diabetes and its management. They can help with any of the issues described in this leaflet.

Diabetes information:

www.diabetes.co.uk

What Is Diabetes? - NIDDK

www.childrenwithdiabetesuk.org

Home - DigiBete

School Sept 2014 Government Guidelines:

Department of Education - Supporting pupils at school with medical conditions.

Expand your network

Why not look at the Diabetes UK Forum for online support:

www.diabetes.co.uk/forum

There is also a Facebook group and a Network website with a dedicated families page:

“South West Paediatric Diabetes Network Parents’ Group”

www.CYPDiabetesNetwork.nhs.uk

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.