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the diabetes information leaflet ...for teenagers ...by teenagers

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Produced by Michelle Gardiner, Lead Children's Diabetes Specialist Nurse, Taunton & Somerset NHS Trust (following a diabetes residential activity weekend, Kilve 2010)

This information leaflet brings together comments made by teenagers with diabetes, telling you what they think you need to know, now you have been diagnosed with diabetes too.

Understanding and learning about diabetes helps you to look after your diabetes better. It is not easy sometimes, but it is important to look after yourself properly to be able to live life to the full and to give yourself the best chance for a healthy future.

What teenagers thought you should know about ‘When you are diagnosed…..’

- You feel thirsty and have been drinking a lot.
- You are hungry and want to eat lots.
- You are ‘peeing’ lots and sometimes it feels a bit uncontrollable!
- You feel angry – especially when you sugar levels are high.
- Trust the doctors and nurses in hospital. You might have to stay in hospital for a couple of days at the start.
- No-one knows what causes it but it is not your fault and you can’t catch it like a cold or chicken pox.
- You will wonder how long it will be until there is a cure
- Try not to worry…
- It gets easier / better in time – teenagers think after about 2 years it’s OK

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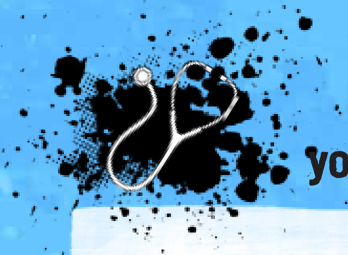

your diabetes team says...

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There are different types of diabetes but the most common are Type 1 and Type 2. Type 1 Diabetes occurs when cells (Islet cells) in the pancreas which make insulin are destroyed by an “autoimmune” process. We do not know what causes or ‘triggers’ Type 1 diabetes and at present there is no way of preventing it. There is often no family history of diabetes but a tendency to develop it may run in families. There may be some connection with viral infections or environmental factors.

The important message is that you cannot catch diabetes (like a cold or flu) and you cannot prevent Type 1 diabetes and it is no-ones fault.

If you suspect a friend or relative has diabetes, do get them to see their GP urgently - early diagnosis is thought to help with getting good control.

what teenagers thought you should know about 'friends and family...

- Families are supportive.
- Some of your friends want to know about diabetes, others want to ignore it (which can be a good thing!)
- Some friends fuss over you and ask if you're OK all the time.
- Some friends are very supportive and help you.
- Brothers and sisters help you.
- Parents help if you are stuck – like with calculations and pinching up for injections – BUT sometimes they are bossy and controlling.
- Parents worry about you.

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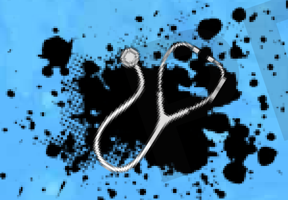

your diabetes team says...

Your parents are likely to feel upset, guilty or disappointed too, and like you they need time to get used to it. There are lots of new things to learn together and they want to help, to support you and make sure you are 'OK'. Sometimes it can seem like parents are being overly protective or restricting what you do, because of your diabetes – keep talking and negotiating. If you show that you are confident and responsible, it will help your parents to feel more confident too! Remember…ASK them if you need their help with anything & try not to 'shut them out' because they worry! It is normal for everyone to feel anxious, scared or angry sometimes.

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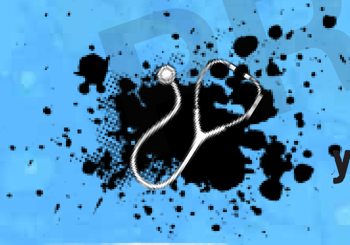
With friends, it is best to be honest and explain about your diabetes from the start. Tell them what to do if you have a diabetic emergency such as a hypo (low blood glucose level). Your friends will probably be very understanding and supportive and it will be easier for you if you don't have to 'disappear' to do blood tests or injections when you are out with them. It is still possible to be discrete when you are socialising and you don't have to shout it from the roof tops!

what teenagers thought you should know about ‘food...’

- All food is good!
- You can still have sweets and chocolate sometimes – like when you are exercising or if your sugar level is low.
- It is important to eat a healthy balanced diet (everyone, not just people with diabetes).
- Food tastes ‘nice’.
- Some foods are high in carbohydrate, like bread, potatoes and pasta, and it is important to eat some of these when you have diabetes.



your diabetes team says...

People with diabetes do not need ‘special food’ and nothing is absolutely forbidden so it’s not about ‘breaking the rules’ or feeling guilty about food – you just need to have a healthy balanced diet. This is recommended for everyone, not just people with diabetes. Sometimes you will need to plan ahead & consider your food choices more carefully.

Carbohydrates (eg. bread, pasta, potato, cereal, rice, fruit juice, milk, sweets etc) are the main food group that, when digested, affect your blood glucose level; some are absorbed more quickly than others. Food is your fuel, so it is important for each meal to contain some ‘starchy’ carbohydrate along with a balance of protein and fat, and of course some of your 5-a-day fruit and vegetables! When you eat carbohydrates you will also need insulin to ensure your blood glucose levels do not become too high (food raises your glucose levels and insulin lowers them).

Food is not medicine, it is meant to be enjoyable and satisfying. Your dietitian will work out a plan with you based on what you like, your routines & what is important to you and your family

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what teenagers thought you should know about ‘blood glucose tests...

- Always wash and dry your hands before you test your sugar level – you can have ‘stuff’ on your hands that might make the result wrong.
- You don’t need lots of blood for a test because the machine ‘sucks up’ what it needs and it’s only a tiny amount.
- Some teenagers said the ‘big’ blood tests hurt less than the finger pricking.
- Most teenagers said doing the finger-pricking is worse than doing the insulin injections.
- Anything under 4 and you need to have a juice (something sugary).
- If your level is high you might have ketones and might need to check for ketones as these can make you unwell.
- Blood glucose tests tell you and your diabetes nurses / doctor if your insulin doses are right.

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your diabetes team says...

Blood glucose testing is important as it helps you and your Diabetes team to decide if your insulin dose needs adjusting. Keeping glucose levels within the ‘target’ range helps you to feel ‘well’ day-to-day but good control is important for keeping you and your body healthy in the future too.

There are many different meters for measuring blood glucose levels but they are all pretty similar in terms of function and accuracy (it only takes a few seconds!). You must wash your hands before testing, prick the side of finger tips and routinely test at least 4 times per day.

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Your Diabetes Team will advise you on the best/most helpful times to test. It is a good idea to write your results down in a monitoring diary as it is easier to spot patterns of high or low readings

You will also have a small amount of blood taken from a vein about once per year, screening for other associated conditions and a longer term blood glucose test (HbA1C from a finger-prick) every 3 months, which reflects your control over the previous 2-3 months.

what teenagers thought you should know about ‘injections...

- Eventually you will get used to them – you are still you!
- They don’t hurt when you get used to it.
- It is important to pinch up your skin otherwise it will go into your muscle.
- Make sure you don’t inject the same place all the time.
- You can inject in your bottom, legs, tummy and arms.
- You must count to 10 once you have put all the insulin in…(if using a pen injector).
- Insulin lowers your sugar level – you need to have injections every day and the number each person needs might be different.

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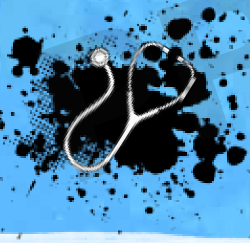
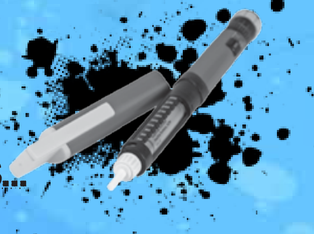


your diabetes team says...



Insulin lowers blood glucose levels. Injections or a pump attached to the body all the time are the only effective ways of giving insulin at present. There are different types of insulin; some work rapidly (with carbohydrate) and some slowly (background insulin).

Injections are usually given with a pen device in the tummy, buttocks, legs or arms. Short 4 or 5mm needles are now used that mean a ‘pinch up’ may not be necessary. You can easily carry insulin ‘pens’ with you wherever you go.

Teenagers with diabetes have multiple insulin injections daily (usually 4) that allow you to eat in the same way that most of your friends do & gives you flexibility over the timing of your meals. You will learn ’carbohydrate counting’- how insulin doses can be matched to the quantity and type of food you choose to eat.

You cannot skip/miss insulin and you must not inject it into the same area every time or the skin will get lumpy and the insulin cannot absorb properly. You will feel anxious or tense at first but injections will get easier as you relax and get more confident.

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what teenagers thought you should know about hypos (low blood sugar levels)...

- You feel shaky or dizzy, sweaty and hot and can't concentrate.
- Sometimes you can shout or get 'silly' or upset and behave different to normal.
- Treat them with glucose tablets (3) or a high sugar drink like lucozade or coke (small glass, 100mls) followed by longer lasting carbs like a sandwich or biscuit.
- They can happen anytime – in the night, after exercise, if you have too much insulin or before a meal (if you are late eating).
- It can be embarrassing if it happens in class or in front of people.
- Diabetic coma because of a serious hypo makes you sick but you don't remember them and they don't happen very often.

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your diabetes team says...

Hypoglycaemia (also referred to as 'hypos') occur when your blood glucose level drops below 4mmols/l. Not everyone has the same symptoms but commonly they include headache, hunger, shakiness / tingling, sweating, looking pale or dark under the eyes and feeling 'wobbly'.

Hypos most commonly happen when you go without food, do lots of exercise or have too much insulin. Other causes include drinking too much alcohol, stress and hot/cold weather. It is possible to reduce the risk of hypos happening by eating regularly, taking the right amount of insulin and planning ahead for activities. Doing regular blood glucose testing also helps as it gives you information about how your body reacts to things; activities, exams and changes in temperature for example.

Feeling like you are losing control is often the worst thing and it is normal to be afraid of having a hypo in public; it can be frightening for people to see you having a hypo if they do not know what to do.
Never ignore the signs – if you detect it early it is pretty easy to treat with quick sugar (like dextrose or fruit juice) followed by a small snack.

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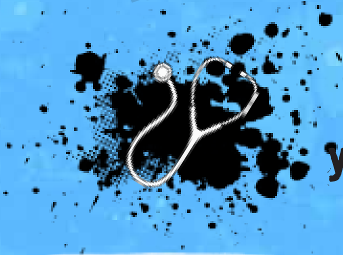
what teenagers thought you should know about exercise / sport...

- Don’t give up doing sport you enjoy just because you have diabetes – you can still do it all.
- Take extra carbohydrate in case you go ‘low’.
- You need different amounts of carbs for different sports and it depends on what you are doing and how long you are exercising.
- ALWAYS have glucose on you.
- If your sport is planned, you could have less insulin instead of eating more.



your diabetes team says...

Exercise is good for everyone. It helps you to look and feel better and also helps to lower your blood glucose levels. Exercise helps to keep your heart, circulation and lungs healthy & helps keep your weight in a healthy range.

Activity helps your body to use insulin more efficiently and also insulin is absorbed more quickly from active sites; both can increase your risk of having a hypo. Hypo’s can happen several hours after lots of activity or intense exercise because your muscles take glucose to replace the stores you have used up.

It is important to plan with your Diabetes team how to get food and insulin right for the exercise/activities that you do.

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what teenagers thought you should know about school...

- Testing your blood at school can sometimes be difficult; practicalities of finding a time and place to do it.
- Games and activities can cause hypos – but you can prevent this if you plan ahead.
- Teachers can 'have a go' at you or might not let you go to the toilet if they don't remember you have diabetes .
- If your sugar levels are high you can be a bit 'out of control', mess around, get cheeky or not listen – this can get you into trouble with the teachers.
- Sometimes other people might call you names or think you are 'faking it'; friends can be a bit insensitive sometimes when you have to take injections or take too long sorting out your diabetes.

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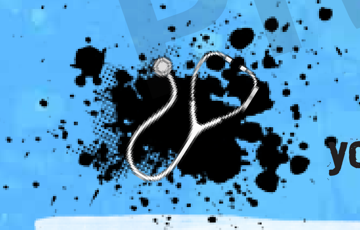

your diabetes team says:

Make sure your teachers and best friends at school know about your diabetes. Introduce yourself to your school nurse too. Don't be embarrassed about it – it will help to keep you feeling safe. Many schools will give you a card or paper slip that you show to your teacher if you are feeling 'unwell' so you can leave the class quickly and easily. It is important to take a 'buddy' with you when going to the medical room to check or treat any problems with your diabetes.

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Wear ID and carry glucose supplies with you in case of hypos – some teenagers (and schools) are happy if you quietly test and treat a hypo in class without disrupting your lesson at all. Keep additional glucose/snack supplies in the medical room in case you need them.

Talk to your Diabetes team about managing things like exams, sport and school meals.
If you are being bullied it can be very frightening and upsetting. Please talk to someone you trust, tell them what is happening so something can be done about it.

what teenagers thought you should know about your diabetes team and you...

- You are still YOU, your life is still the same but you have to be careful with sugar.
- Diabetes only takes a bit of time out of your day and that time might be out of school!
- The diabetes team are friendly.
- Listen to what the diabetes team say and put it into action (13 out of 15 teenagers said listen, coz they listen!)
- The diabetes team are good to talk to when you need it or when you have questions to ask.
- The diabetes team are the best!

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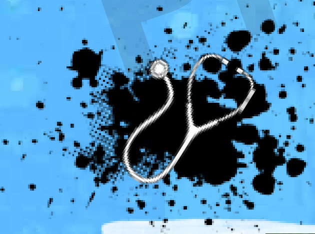
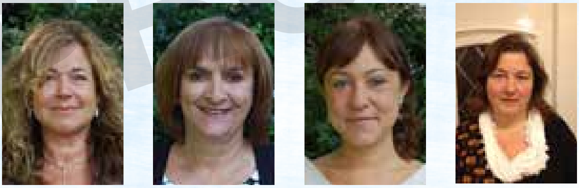


your diabetes team...

Consultant Paediatricians



Children's Diabetes Specialist Nurses

Clinical Psychologist

Dietitians

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other things teenagers with diabetes think you should know...

- It is important to always take your injections and do blood sugar testing.
- The finger-pricking doesn't hurt!
- You will get fed-up of doing so many tests and injections and feel really cross sometimes; especially when people think you are 'lucky' to have diabetes because you get out of lessons and can eat all the time.
- Diabetes won't change your life, it does not need to make everything different.
- Being diabetic is not necessarily because you are fat.
- Diabetes knowledge can sometimes be useful eg. in a debate about animal testing at school or for projects.
- Teachers don't always understand about diabetes.
- Always wear your 'alert tag' (medical ID).
- Don't worry – there is always support out there for you.

This information leaflet has been produced using direct quotes and comments from the group of teenagers with diabetes attending Kilve 2010 weekend. We thank them for sharing their honest views and experiences with us, their diabetes team.

We also thank the Josh Evans Fund for supporting children with diabetes in Somerset by sponsoring the publication of these leaflets.

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other resources your might find helpful...

- www.diabetes.org.uk
- www.diabetes.org.uk/MyLife - reliable information on diabetes and support, including sections for children and young people.
- www.childrenwithdiabetesuk.org - website for families.
- www.jdrf.org.uk - a charity particularly interested in fundraising and research.
- www.runsweet.com - a website about exercise and diabetes.

podcasts

- http://www.nnuh.nhs.uk/Page.asp?ID=260&q=diabetes,podcast - podcasts for families and young people on different aspects of having diabetes.
- http://www.dawnstudy.com/action_area/living_with_diabetes/living_noras_notes.asp - information from a young person on living with diabetes.

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If ever you are uncertain about anything you read about diabetes, please ask a member of your diabetes team. The inclusion of a website or other resource does not indicate endorsement by Taunton & Somerset NHS Foundation Trust.

local support networks

- www.joshevanstrust.org – The Josh Evans Charity, supporting children with diabetes in Somerset.
- www.balancebuddies,co,uk - Balance Buddies Support Group.

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your diabetes team contact details...

During office hours contact the children's diabetes specialist nurses. However, if you need urgent advice and your call is not answered, do not leave a message, but instead call the on-call paediatric registrar as below
01823 343666
Evenings, weekends and bank holidays, contact the on-call paediatric registrar via the Children's Unit
01823 342016

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