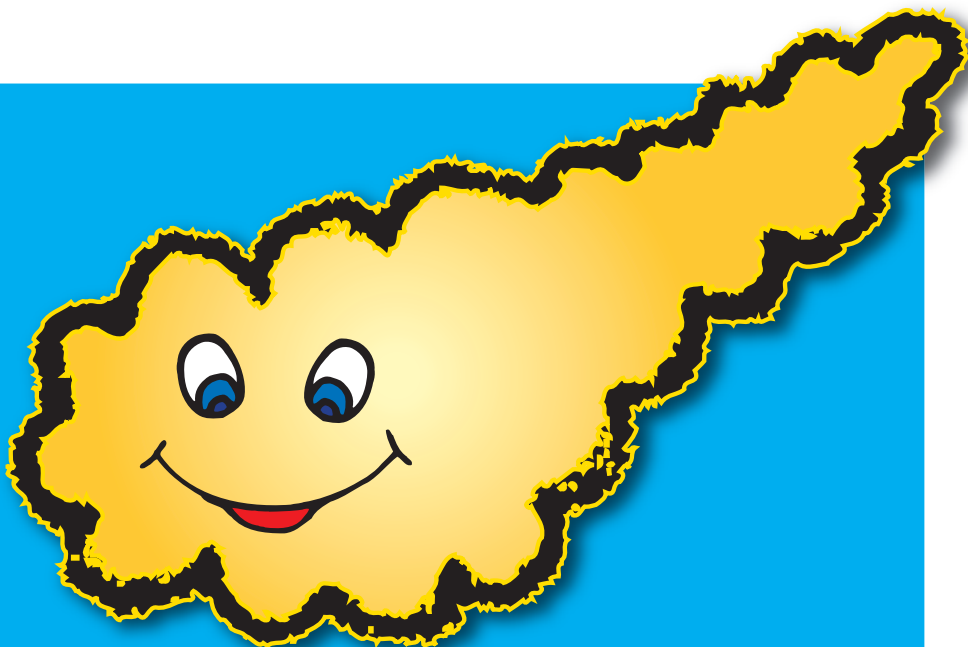


diabetes education for parents



PETE THE PANCREAS

Helping you and your child
understand their diabetes.

changing diabetes®



Contact details

Hospital: _____

Phone: _____

Doctor: _____

Phone: _____

Other useful numbers

Diabetes nurse specialist: _____

Diabetes clinic appointments: _____

Out of hours contact no.: _____

Dietician: _____

Family doctor: _____

Other: _____

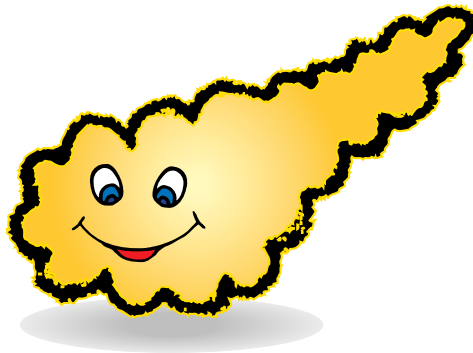
Who is this booklet for?

This booklet is for parents or guardians of children who have been diagnosed with diabetes.

It is designed to accompany 'Meet Pete the Pancreas', a booklet which explains diabetes in simple terms for your child.

The aim of this booklet is to provide you with information and guidance that will help you help your child.

If you need any more advice, or have any worries, your child's doctor or nurse will be happy to help.



Acknowledgements

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A diagnosis of diabetes

Your child has not been feeling well, probably for some time.

Typically they will have felt very tired, thirsty and hungry, needed to urinate frequently and possibly lost some weight.

A diagnosis of diabetes can be very frightening for you and for your child.

From now on, your child will always have to take extra special care of themselves in order to remain healthy.

This can be very hard for a child to understand, and they will need your help and support as they adjust and learn to look after their diabetes.

However, the good news is that diabetes is something that we know a lot about - there are very good treatments currently available and research is ongoing into even better treatments.

There is no reason why - with good education and care - your child cannot live a long, happy and healthy life.

What help is available?

During diagnosis, your child has probably already been in hospital and you will have established contact with your diabetes team who will be responsible for your child's ongoing care.

Typically, a diabetes team consists of:

- Doctors
- Diabetes nurse specialists
- A dietician.

Other professionals may be called in to help, depending on your child's needs, e.g.:

- Play specialists
- Psychologists
- Social workers.

All of these people will play a vital role in helping your child come to terms with their diabetes and learning how to look after themselves.

Before going home from hospital the diabetes team will ensure that you have everything you need to manage your child's diabetes.

After discharge the diabetes nurse may be in contact with you every day for a few days. As you grow in confidence, this contact will become less frequent.

Children are usually seen in out-patients every 3-4 months.

Once a year a longer visit will be scheduled for a more thorough checkup.

If you are in doubt about any aspect of your child's diabetes, never hesitate to give your child's doctor or nurse a call.



What is diabetes?

- Diabetes is a long-term disorder characterised by a raised level of glucose (or sugar) in the blood.

'Blood glucose' and 'blood sugar' mean the same thing

Where does glucose come from?

- Glucose comes from food, particularly starchy and sugary foods
- Digestion breaks down carbohydrates into glucose which is then released into the bloodstream



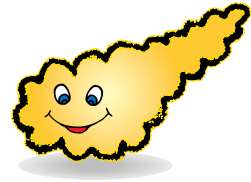
- Some foods provide glucose very quickly, e.g. jams, sweets and fruit juice
- Other foods provide glucose slowly, e.g. potatoes, bread and rice



It is important that your child realises the words 'glucose' and 'sugar' mean the same thing. They are used interchangeably in diabetes care.



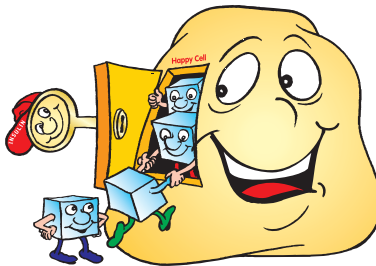
- The pancreas (a gland in the body near the stomach) makes a hormone called insulin.
- Insulin is very important – it helps glucose move from the bloodstream into the cells of the body which need it to make energy.



Pete the Pancreas

When a child develops type 1 diabetes the pancreas stops making insulin. Without insulin, glucose cannot move into the cells but stays in the bloodstream and then spills into the urine. As a consequence, the cells of the body are starved of energy and start to breakdown fat stores which produces ketones (see page 22). High levels of ketones in the blood are dangerous and can cause diabetic ketoacidosis which can make a child very ill.

Insulin acts as a key, unlocking the door to cells to let the glucose in.



Why did your child develop diabetes?

Most children with diabetes have type 1 diabetes

Insulin-making cells in the pancreas are known as 'islet cells' or 'beta cells'. In type 1 diabetes these cells are destroyed. There are certain genetic features which make some individuals more vulnerable to developing type 1 diabetes. Factors in the environment also contribute and research is ongoing to try to better understand these factors.

Is there anything you or your child could have done to prevent the onset of type 1 diabetes?

No. At the moment there is no way of preventing type 1 diabetes.

Is there a cure for diabetes?

Although research is being carried out all over the world there is currently no cure. Type 1 diabetes always has to be treated with insulin which is injected using a very fine needle. Whilst there have been recent developments in pancreatic and islet cell transplantation, this approach is still experimental.

Research is ongoing to improve the lives of individuals with type 1 diabetes.

Your child has type 1 diabetes.

There is nothing you or your child could have done to prevent their diabetes.

Are there different types of diabetes?

Yes, there are several types of diabetes

Type 1 diabetes (the type most children have)

- Is when the pancreas stops making insulin
- Most of the insulin-producing cells have been destroyed
- Occurs more frequently in childhood
- Insulin injections are always needed.

Type 2 diabetes

- Occurs when the body makes some insulin, but not enough to meet requirements
- Occurs more frequently in adulthood
- Can be influenced by lifestyle factors
- Treatment often starts with lifestyle changes only, i.e. diet and exercise
- Oral medication and eventually insulin are often needed to control blood glucose levels.

Gestational diabetes

- Occurs in some women during pregnancy
- After childbirth blood glucose levels usually return to normal
- There is an increased risk of developing type 2 diabetes in later life for women who have had gestational diabetes.

Cystic fibrosis related diabetes

- Cystic fibrosis is a chronic condition which mainly affects the lungs and pancreas
- Some patients with cystic fibrosis develop diabetes.

What daily care will your child need?

After being diagnosed, and especially if your child is very young, he or she will need a lot of help managing their diabetes day to day.

This means that YOU need to acquire a new skill set too!

You will need to:

- ✓ Learn about blood glucose levels, how to monitor, record and interpret them
- ✓ Learn how to give your child an insulin injection - and when they are ready, guide them to do it themselves
- ✓ Learn about how diabetes will affect their diet, what and when they should eat and how to count carbohydrates
- ✓ Learn the signs and symptoms of a low blood glucose level (hypoglycaemia) and how to treat it
- ✓ Learn the signs and symptoms of a high blood glucose level (hyperglycaemia) and how to treat that
- ✓ Learn how to treat your child's diabetes when they are sick.

It is important to involve your child as much as is practical in the care of their diabetes. Listen and give them as much time and attention as they need.

Ultimately, your goal should be for you and your child to be able to independently manage as much of the routine care by yourselves as possible.

Psychologically, your child may find it difficult to understand and to deal with having diabetes. Sometimes children experience anxiety, depression or behavioural difficulties at home or at school.

Your diabetes team will be experienced in dealing with all types of issues that may arise and will be able to refer you on to individual specialists if required.



Why does your child need to check their blood glucose levels?

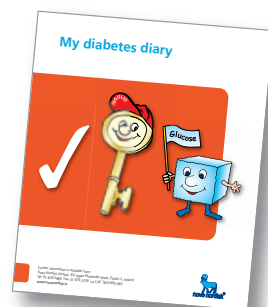
- ✓ Monitoring blood glucose levels gives you, your child and the diabetes team information on their diabetes control and allows insulin dose adjustments to be made as necessary
- ✓ Your child will be given a home monitoring diary to record their blood glucose levels. It is important to keep accurate, frequent blood glucose diary readings and to bring the diary with you to each visit at your diabetes centre or clinic
- ✓ Some meters have memory to record results
- ✓ You will be given guidance on how best to adjust your child's insulin at clinic based on your diary results.

Good control of their diabetes helps keep your child healthy

Research shows that high levels of glucose in your child's blood over a long time can cause problems with:

- Eyes
- Kidneys
- Heart
- Nerves
- Blood circulation
- Legs and feet.

However, with good diabetes control the risk of developing these problems is significantly reduced.



What should your child's blood glucose level be?

Daily blood glucose monitoring

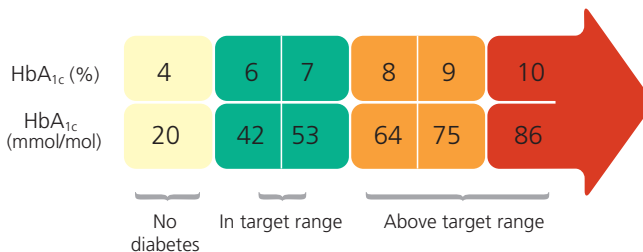
- Blood glucose is measured in millimoles per litre (mmol/L)
- In general, you should aim to keep your child's blood glucose level between **4.5 and 9.0 mmol/L**; however your child will be given an individual target by their doctor or nurse
- The doctor or nurse will teach you and your child how and when to test your child's blood glucose level and how to know if you need to change your child's insulin dose depending on the results.



HbA_{1c} readings

- For their clinic visits, your child will have a blood test done called a HbA_{1c}. This gives an estimate of their blood glucose control over the preceding 2 - 3 months.
- During 2010 a new type of measurement was introduced for this test, so you will either get the result as a percentage - e.g. 7% - or in millimoles per mol - e.g. 53 mmol/mol. By the end of 2011 you will only get this reading as mmol/mol.

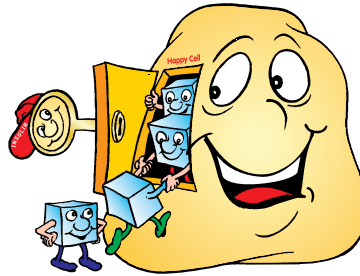
Your child will be given a target by their doctor or nurse, based on their individual goals.



Keeping this reading within target range has been shown to prevent or delay the onset of complications of diabetes.

What do you need to know about insulin?

Remember!
Insulin acts
as a KEY



Insulin opens the cells in your child's body so that glucose can be let in and converted into energy.

As your child's body no longer produces its own insulin, your child will now need manufactured insulin - which does exactly the same job!

Insulin is destroyed by gastric acid in the stomach which is why it currently cannot be given as a tablet. However, research is ongoing into this method of delivery so maybe in the future ...

But for the moment, your child will need to have insulin injections on a daily basis.

There are many different brands and also many different profiles of insulin - some stay in the body for a long time, some for a short time. Your child's doctor or nurse will advise what insulin or insulins your child requires.

Insulin can come:

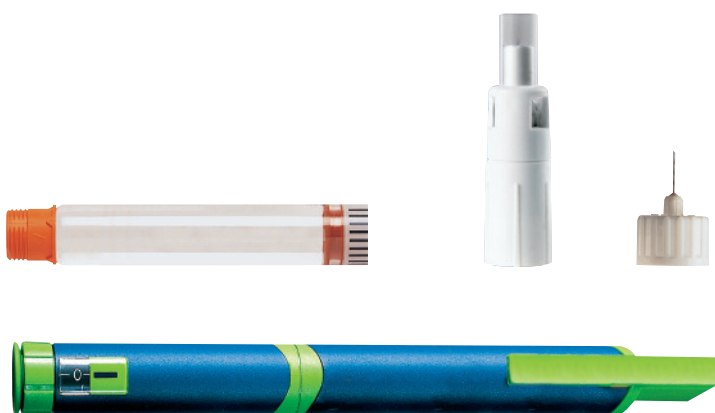
- In a vial with a syringe
- In a durable injection device, similar to a pen, with an insulin cartridge
- In a disposable injection device
- In a pump, which is a continuous infusion.

Again, your child's doctor or nurse will advise as to the best method of delivery for your child.

Needles are much smaller and less painful than they used to be. However if your child has a phobia of needles, there are devices available which cover the needle while they inject.

Your child's doctor or nurse will show your child how to inject properly and effectively causing little or no pain at all.

Contact the diabetes clinic or pharmacy if you need a spare or replacement device.

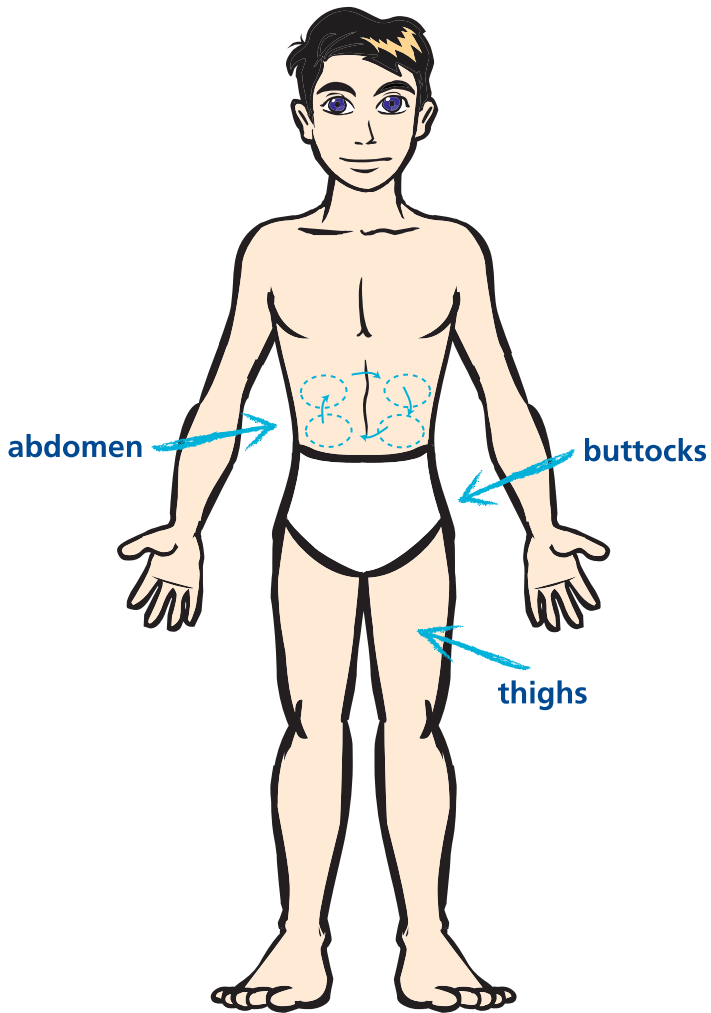


All insulins vary in onset of action, duration of action and when the maximum effect is reached. Please consult your child's diabetes team for more details of your child's insulin.

Where is the best place to inject insulin?

- The fatty areas of your child's body - abdomen (tummy) or thighs - are the best places to inject insulin. Other places which can be used include the buttocks.
- Don't worry – injecting insulin is easy, you and your child will be shown how by your child's doctor or nurse.
- Your child shouldn't inject in the same spot all the time as it can cause lumps in their skin. These lumps stop the insulin from working properly.
- Your child's doctor or nurse will give you more advice on:
 - Injection techniques
 - Rotating injection sites
 - Adjusting your child's insulin dose
 - Disposing of the needles.

Injection sites



What if your child has a low blood glucose level?

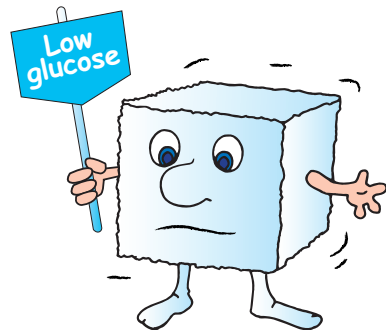
Hypoglycaemia is the medical word for low blood glucose levels.

Hypoglycaemia is often called a **'hypo'** for short. Definitions of low blood glucose levels vary. Most children will have no symptoms unless their blood glucose level is 4.0 mmol/L or less. For safety, blood glucose levels of 4.5 mmol/L or less are sometimes treated as being a 'hypo' in young children. Check with your doctor or nurse what is appropriate for your child.

How will your child feel?

Your child may have low blood glucose levels and not know it. Other times they may be:

- Anxious
- Behave oddly
- Confused
- Pale
- Sweaty
- Hungry
- Weak
- Shivery/shaky
- Be uncooperative (unable to drink)
- Complain of blurry vision
- Have a pounding heartbeat



If left untreated they may have a seizure (lose consciousness).

A 'hypo' can develop quickly (within minutes).

What causes hypoglycaemia?

- Too much insulin
- Missing meals or snacks
- Insufficient carbohydrate in meals or snacks
- Exercise without adjusting routine
- Illness (e.g. gastroenteritis).

What should you do if your child has a 'hypo'?

Get your child to drink or eat something containing sugar immediately, e.g.:

- 50mls of Lucozade original (other types of Lucozade contain varying amounts of glucose)
- 100mls of ordinary (not diet) fizzy drink (e.g. 7UP, Fanta, Coke)
- 100mls of fruit juice
- 3 Lucozade sweets
- Any other form of sugar e.g. honey or jam etc., if none of the above are available
- If the next meal is not due within an hour, they should have a small snack, e.g. bread, fruit
- If your child is unable to take any of the above they can be given Glucogel
- **IMPORTANT! If your child is unconscious you should not put anything in their mouth.**

- Check your child's blood glucose level after 15 minutes
- If your child still doesn't feel well and their blood glucose level remains less than 4.5 or 4.0 mmol/L (as advised), repeat the above
- When your child's blood glucose level goes back above 4.5 or 4.0 mmol/L (as advised), they should then eat their next meal if due
- They should take their insulin as normal
- If your child does not respond as above, this may be a severe 'hypo'.

Your child's diabetes team can give you advice on severe 'hypos' and what to do if your child becomes unconscious. They may have to be given an injection of glucagon. It is important that you, your family and your friends know how to do this.

You need to make sure that anybody who is regularly in contact with your child - teachers, sports coaches, friends, parents of friends - is aware of the possibility of your child having a 'hypo'.

It is advisable for your child to always carry with them:

- Glucose tablets or some form of sugar
- Identification to say that they have diabetes

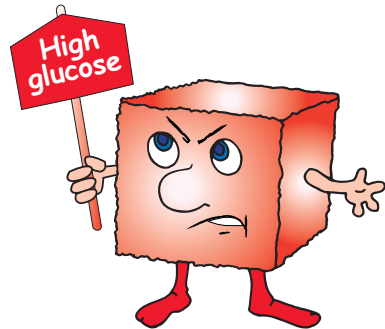
What if your child has a high blood glucose level?

Hyperglycaemia is the medical word for high blood glucose levels.

How will your child feel?

Your child may have high blood glucose levels and not know it. Other times they might be:

- Flushed
- Lethargic
- Thirsty
- Urinate frequently
- Grumpy
- Complain of stomach pains
- Off form, no energy



These symptoms may develop slowly, over hours or even days.

What causes hyperglycaemia?

- Not enough insulin or forgetting their insulin dose
- Too much of the wrong kind of food or drink (too sugary)
- Illness.

What should you do when your child has a high blood glucose level?

- Don't panic - it is normal for blood glucose levels to go up and down in a day
- Test for ketones (see page 22)
- Check blood glucose levels more frequently and record results
- Think if there is any logical reason for the high - extra sugary food, has your child taken their insulin correctly?

Emergency situations

**If your child is:
Vomiting and unable to hold down fluids or
Has high blood glucose levels and ketones
in their blood or urine**

**Contact your child's doctor or nurse or dial
999/112 immediately.**

What are ketones?

Normally, with the help of insulin as a 'key', the body uses glucose from food to produce energy.

When there is little or no insulin to allow the conversion of the glucose from food into energy, the body starts breaking down fat for energy.

When this occurs, 'ketones' form in the blood and spill into the urine.

These ketones can make your child ill and if left untreated eventually lead to 'diabetic ketoacidosis' or DKA, a potentially life threatening condition.

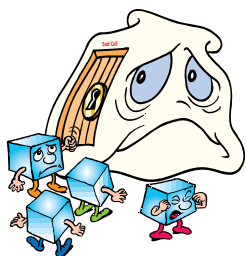


How do you test for ketones?

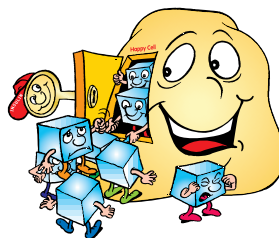
You can test for ketones in the blood or urine. Several products are available for doing this - your child's doctor or nurse will advise you.

When should you test for ketones?

- If your child's blood glucose level is over 15 mmol/L
- When your child is ill



Lots of ketones



Now the ketones
will go away



What should you do if the ketone test is positive?

- Your child may need additional insulin - call your child's doctor or nurse to confirm
- Ensure that your child drinks plenty of water or unsweetened fluids
- Continue to test blood glucose levels and ketones every 1-2 hours

Ketone levels can be checked in two different ways - in blood or in urine.

Information for patients testing for ketones

If your blood ketone level is:

Less than 0.6 mmol/L

This is fine! Just go on testing your glucose as usual.

Blood ketone reading:
between 0.6 and 1.5 mmol/L

Urine ketone reading: +

This is a bit high. You should test your glucose and ketones again in 2-4 hours time. You may need extra insulin. Contact your doctor or nurse for advice.

Blood ketone reading:
between 1.5 and 3 mmol/L

Urine ketone reading: ++

You may be at risk of developing DKA (diabetic ketoacidosis). You will need to take extra insulin. Call your doctor or nurse immediately for advice.

Blood ketone reading:
more than 3 mmol/L

Urine: +++ or ++++

You require immediate emergency treatment - go straight to your nearest Accident and Emergency department.

It is very important that you and your child are aware of ketones and how to test for them.

Sick day rules

When ill, even if your child is not eating, blood glucose levels tend to rise. It is very important to monitor blood glucose and ketone levels and seek medical advice if concerned.

What should you do when your child is ill?

- Seek medical advice with your General Practitioner for the underlying illness
- Never stop administering insulin
- Test blood glucose levels / ketones every **2** hours
- **Obtain medical advice if they are vomiting and ketones are present**
- Drink plenty of unsweetened fluids e.g. water
- If unable to eat, substitute meals with regular sugary drinks (non diet) but check with your child's doctor or nurse how much they should take.



If you feel your child is very unwell or not improving always seek medical advice.

Everyday life with your child

No matter how scared and worried you might feel at the time of diagnosis, life will and does go on.

As with any new set of skills, the ones you need for looking after your child's diabetes will take a little time to acquire.

And as with all other parenting issues, patience is key.

Most children will find some aspect of their diabetes difficult, whether it is injecting insulin or modifying their diet.

Play therapy can be very effective in helping young children come to terms with their diabetes and some of the larger hospitals may be able to offer a specific play programme with a play specialist.

A play specialist will work to alleviate any fears your child might have about their diabetes and clear up any misconceptions they may have picked up during diagnosis.

They will use various methods to do this, using shared activities such as reading books about diabetes, practising injection techniques with toys and motivation and reward systems when your child achieves their personal milestones.



School

It is important that your child's school principal, teacher and other relevant staff are aware that your child has diabetes.

You should provide the school with written information from the hospital for teachers and ensure that they have:

- Your contact details
- Your child's diabetes team contact details
- A hypo remedy available at all times.

You will need to provide information to the school and the class teacher about your child's regime, when they need to eat etc. It is a good idea to write this down and ensure that several people - e.g. the teacher, principal, school secretary - have a copy.

Speak to the principal and class teacher about the possibility of substitute teachers - often this happens at the last minute and they should have provision in place to make sure that anybody taking your child's class is aware of your child's diabetes.

There will be a little more planning required now when your child goes on a school trip. You will need to plan their food and insulin with them in advance and make sure that the teacher/helpers on the trip are aware of their requirements and what to do in an emergency.

The Diabetes Federation of Ireland booklet, 'Your Student with Diabetes' is a comprehensive guide which you can give to your child's teacher. It is available by phoning the Federation on 1850 909 909 or to download from www.diabetes.ie.



Play and sport

Your child will be able to participate in every activity they did before they had diabetes and maybe quite a few more.

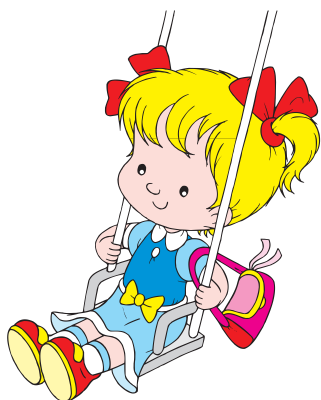
Exercise is a very important part of keeping healthy for everyone.

However, exercise uses up glucose so you need to make sure that your child is aware that when they are planning exercise they will need to adjust their routine as advised by their dietician.

This applies to just the normal running around type of exercise as well as structured exercise.

Any sports coaches should be aware that your child has diabetes, and as with teachers you need to ensure that they know what to do in case of an emergency while your child is in their care.

Our 'Pete the Pancreas - Explanatory guide for carers of children with diabetes' provides a broad outline of what people should be aware of when caring for your child.



Friends and socialising

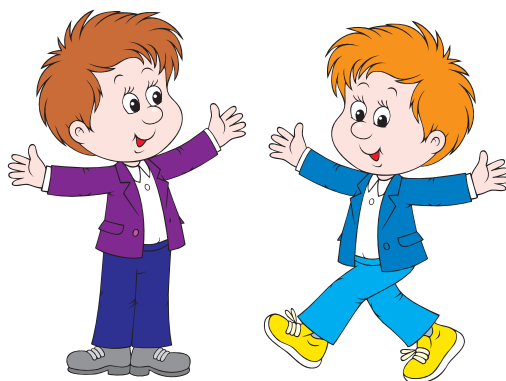
Children are very social creatures. As they grow, most parents find themselves juggling a never ending round of play dates, parties and sleepovers.

A major challenge for you will be to ensure that all your children's friends are aware that your child has diabetes, why this makes them special, what they can't eat too much of and what they need to do in an emergency.

When you are leaving your child in the care of another parent, you need to make sure that they are fully aware of your child's needs regarding their diabetes during that time and what to do in case of an emergency.

Parties can be especially stressful for your child if they see other children over-indulging in sweet things. Talk to your child before any such event and agree with them their own individual limits. There are no foods your child cannot have - they just may not be able to have the quantities that others do.

You might find it useful to give our 'Pete the Pancreas - Explanatory guide for carers of children with diabetes' to the parents of your child's friends.



More information

Remember you are not on your own - around 2,000 children in Ireland alone have type 1 diabetes.

Support groups such as the Diabetes Federation of Ireland can offer great advice and contact with other people who are in the same situation.

Above all, never forget your child is still an 'ordinary' child. There is nothing that they cannot do because they have diabetes.

For further information see:

Diabetes Federation of Ireland
Lo Call 1850 909 909
(www.diabetes.ie)

Online community for kids with diabetes and their families'
(www.childrenwithdiabetes.com)

Diabetes Ireland Research Alliance
(www.diabetesresearch.ie)

Diabetes UK
(www.diabetes.org.uk)

American Diabetes Association
(www.diabetes.org)

International Diabetes Federation
(www.idf.org)



Diabetes Federation of Ireland

Supporting people with diabetes

Would you like to:

Meet other parents and share experiences and knowledge of Type 1 diabetes

Participate in family, social and educational activities

Keep up to date with developments in diabetes

**For more information contact the Diabetes Federation of Ireland on
Lo-call 1850 909 909/01 8363022 or visit www.diabetes.ie**

Diabetes Federation of Ireland, 76 Lower Gardiner Street, Dublin 1
Diabetes Federation of Ireland is a registered charity (CHY 6906)



Would you like to:

Keep up to date with diabetes research developments

Support global and Irish based research into Type 1 diabetes

**For more information contact the Diabetes Ireland Research Alliance
on 01 8764577 or visit www.diabetesresearch.ie**

Diabetes Ireland Research Alliance (CHY 18304)
is the research charity of the Diabetes Federation of Ireland,
76 Lower Gardiner Street, Dublin 1

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This booklet is provided as an educational service to people with diabetes by:
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Tel: 01 678 5989 Fax: 01 676 3259 Lo Call: 1850 665 665
www.novonordisk.ie info@novonordisk.ie



Now your child has been diagnosed with diabetes it means that you will have to make a few changes to your everyday lives.

At Novo Nordisk we have worked with children with diabetes for many years and we understand that it can sometimes be a bit difficult.

We want to make it easier for you by making looking after your child's diabetes as simple as possible.

Then all you and your child have to do is get on and enjoy life!

changing the future of diabetes



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Version 3.0



Further information is available from: Diabetes Federation of Ireland
Lo Call: 1850 909 909 info@diabetes.ie www.diabetes.ie