



HOW TO LIVE WITH DIABETES

A guide with general lifestyle information

www.withyoualltheway.info

changing diabetes®

At Novo Nordisk, we are changing diabetes. In our approach to developing treatments, in our commitment to operate profitably and ethically and in our search for a cure.



With you all the way is a paediatric support programme created by Novo Nordisk, providing practical information on diabetes and its management for you and your child.

This material has been reviewed by a panel of experts:

- Lead Diabetes Specialist Nurse – Nicola Lewis, UK
- Paediatric Endocrinologists – Prof Thomas Danne, Germany and Dr Nandu Thalange, UK



This information is not designed to replace the advice of a healthcare professional. Please consult your healthcare professional if you have any questions or concerns about your child's condition.

Living with type 1 diabetes

Following your child's type 1 diabetes diagnosis, monitoring and insulin treatment will have become part of your family's daily routine.

As your child grows and develops, their needs will change and they will become more independent. It is likely they will want to take a more active role in the management of their diabetes. They should be encouraged to maintain a healthy lifestyle to help achieve blood glucose control.

It is also important that they are fully aware how to manage their condition when away from home.

We hope the information in this booklet will answer some of the questions you may have about caring for a child growing up with diabetes.

Growing up with diabetes

As your child develops, the challenges you face in managing their diabetes are likely to change as they grow.¹ Your healthcare professional and diabetes care team are the best ones to advise you on diabetes care during particular phases of your child's growth, but here are some typical challenges:¹

Infants and toddlers (up to 36 months) –

Big fluctuations in glucose levels due to irregular food intake.

Preschoolers and primary school (3–7 years) –

Unpredictable appetite and activity levels.

Children of older school age (8–11 years) –

Making diabetes care flexible enough to allow for participation in school/peer activities.

Adolescents – Managing increased needs for insulin that may occur during puberty as children grow up and gain independence and sharing responsibility between parents and teenagers.



The importance of maintaining a healthy lifestyle

Healthy eating is important, for people with or without diabetes.^{2,3}

Your child will probably see a dietitian as part of their diabetes care team who will provide advice on how much your child should eat, depending on their age and weight. The recommendations are usually not unlike those for people without diabetes – a healthy, balanced diet containing adequate fibre and carbohydrates, adapted to cultural, ethnic and family traditions and the individual needs of your child.⁴

Generally, children with diabetes are advised to eat three main meals each day with snacks in between, if necessary.⁴ Usually a child can follow the same healthy eating habits as the rest of the family and does not require a special diet.

Having type 1 diabetes doesn't mean they can't eat any sweets as treats.^{2,3} When you learn how your child's body responds to eating and taking insulin they will be able to have sweets in moderation, along with the appropriate insulin.^{2,3} Planning meals in combination with monitoring and adjusting insulin can help to improve your child's blood glucose control.⁴

Working together, you and your child's dietitian should be aiming to promote a positive relationship with food, while providing all the nutrients your growing child needs.²

For more information, please refer to the 'What to eat?' information leaflet provided in this pack.



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Physical activity

Regular exercise is recommended for all children with or without diabetes.^{5,6} Daily physical activity should become part of your child's routine for health benefits and consistency in blood glucose management.⁵

It is important to be aware that physical activity lowers blood glucose, so insulin doses or food intake may need to be adjusted prior to exercise.⁵

Short periods of intensive exercise ("anaerobic exercise") can also elevate blood glucose levels. If there is significant hyperglycaemia, ketones should be tested as exercise may lead to diabetic ketoacidosis (DKA).

The combination of too much insulin and exercise can lead to low blood glucose or episodes of hypoglycaemia.⁵ Hypoglycaemia may be prevented by lowering your child's insulin dose for the meal beforehand and by having some fruit juice or a long-acting carbohydrate snack before exercise.^{2,6}

After very strenuous exercise it is important to have a meal with a good amount of complex carbohydrates, and sometimes to reduce the dose of long-acting insulin the evening after exercise, to reduce the risk of night-time hypoglycaemia.

Your child should test their blood glucose prior to exercise to learn how their body reacts to exercise and ensure appropriate insulin dosing. Testing after exercise may help you to see how exercise affects your child's blood glucose levels.^{2,6}

If activity or exercise is planned, you should adjust the insulin dose or food intake accordingly.

If your child has a more active day than usual, for example running around more than usual, you may need to increase their food intake afterwards to help maintain blood glucose levels or reduce the insulin appropriately (e.g. choosing a temporary basal rate on pump).

LIAM AND JORDAN CARSTENS

South Africa
Liam and Jordan have type 1 diabetes

The importance of monitoring blood glucose control

Your child's healthcare professional will advise when and how much insulin your child needs each day and will teach you how to monitor glucose independently.

Regular checking of blood glucose levels is important to help avoid hypoglycaemia or hyperglycaemia, and to meet your child's changing needs. You should be aiming to maintain glucose control without frequent disruptive episodes of hypoglycaemia.⁶ Ideally, your child should aim to achieve the following long-term blood glucose targets:^{2,6}

- Before a meal – levels should be between 4.0 and 8.0 mmol/L (72–144 mg/dL)
- 2 hours after a meal levels should be no more than 10.0 mmol/L (180 mg/dL)
- At bedtime levels should be between 7.0 mmol/L and 10.0 mmol/L (126–180 mg/dL)

These targets can be hard to achieve and it is unlikely your child will reach these levels when they start using insulin. If you struggle to achieve target levels over a long period of time, contact your healthcare professional.

Long periods of poor blood glucose control and sustained high blood glucose levels can lead to long-term complications.⁷ The International Society for Paediatric and Adolescent Diabetes (ISPAD) recommend that children of all ages should aim for a blood glucose level below 7.5% (10.6 mmol/L or 190 mg/dL) to avoid such complications. Monitors will vary and have different limits. If your child's reading is above this upper limit, the monitor will show 'high'. Check the instructions that come with your monitor for more details.

If your child is not achieving target levels, speak to your healthcare professional about your child's management plan.



Diabetic ketoacidosis

If left untreated, high blood glucose in diabetes can be dangerous and could lead to a severe condition called diabetic ketoacidosis (DKA). Signs of DKA include:^{2,3}

- Nausea and vomiting
- Stomach pain
- Fruity breath odour ("ketones") – often described as pear drops or nail varnish smell
- Rapid breathing
- Dehydration (e.g. dry tongue, less frequent urination/dry nappy)
- Increased blood glucose levels

This can happen rapidly, particularly in young children. If your child has any of these symptoms, you must seek emergency medical attention. If available you should measure ketones in the urine or blood using the appropriate test strips.

Care away from home

At school

When your child starts school, or returns to school after diagnosis, it is important that people involved in their care are aware of their needs.

You may find their teachers have experience looking after other children with diabetes, or it may be something they are unfamiliar with.² In any case, each child's diabetes is different and each child will have a personalised plan for managing meals, hypoglycaemia, hyperglycaemia and exercise etc. You may worry about leaving your child in someone else's care but, with the right information and training, school staff should be able to provide the appropriate care to manage your child's condition.²

Even if your child is old enough to test their blood or inject their own insulin, they will still require supervision by a responsible adult.¹

It may help if your child or their teacher keeps a diary of blood glucose levels especially if any episodes of hypoglycaemia occur that you can read at the end of the day.² Your child should carry a clearly labelled 'Hypobox' with them which contains information and supplies to help manage hypoglycaemia.

You will need to arrange a meeting with your child's teachers and diabetes care team to discuss your child's needs and what level of help they will need at school.²

It may help to show teachers/other support staff the 'What about diabetes at school?' information leaflet supplied in this pack.

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Meeting your child's needs at school

Here are some ideas of points you may want to cover when you meet with school staff:²

■ **Emergency contacts**

- Who should they contact in case of a problem? You may want to provide details of another family member or friend in case they can't get hold of you

■ **Management of hypoglycaemia**

- What signs should they look out for and what do they need to do?
- Where will emergency supplies (e.g. Hypobox) be kept?
- Will school nurses/teachers have access to glucagon for use in emergencies?

■ **Mealtimes and snacks**

- If they need to eat at particular times, how will this fit into the school timetable?
- Will they have a packed lunch or school lunch?
- Do they need help with choosing meals or carbohydrate counting?
- Do they need a snack before physical activity?

■ **Blood glucose testing**

- When should this be done and does your child need assistance?
- What do the results mean?

■ **Management of hyperglycaemia**

- What should they do if your child has high blood glucose?

■ **Insulin dosing**

- Does your child need to inject insulin during the school day and do they need assistance? Or, if on an insulin pump, can they control their pump themselves?
- Is refrigeration available? (if required in hot climates)
- Is there somewhere quiet and private they can inject?

You will need to ensure that your child has all the equipment and supplies they need for management of their condition during the school day. You should check supplies regularly and replenish as necessary.

School trips/ sleepovers

There is no reason why your child can't go on school trips or stay at a friend's house as long as they are prepared and the people looking after them are confident managing their condition.²

Tips

- Talk to your child's teachers or other parents to ensure they know how to manage their condition – you may want to arrange a meeting prior to the trip or additional training
- If they will be staying away overnight, ensure they are aware of signs of night-time hypoglycaemia and how to manage events should they occur
- Find out what activities are planned and what meals will be provided. You may want to give them a packed lunch if it is a day trip
- Ensure they have enough insulin with them for all doses required and that refrigeration is available, if required in hot climates
- Ensure they have adequate supplies of fast-acting carbohydrates e.g. glucose tablets, sweets or cartons of fruit juice, to help manage hypoglycaemic episodes should they occur



After school activities/parties

As your child gets older they may be interested in taking part in activities or clubs after school. They may also be invited to parties at other children's houses.

Tips

- Ensure staff supervising or other parents are aware of your child's needs and know how to manage their diabetes²
- If they are going to parties, find out what food will be available at the party and discuss with the other parents what and how much your child can have
- If they are taking part in physical activity, think about whether they will need an extra snack or a different insulin dose²
- If the activities/party interferes with their normal dosing routine, speak to your healthcare professional to see whether the dose can be taken later²

Older teens/young adults naturally want independence from their parents. As they start going out with friends and partying, it can become more difficult to supervise what they may be eating or drinking and knowing they are taking insulin correctly. There are no specific rules for parents, regardless of how long your child has been diagnosed. Whilst your child may behave like any other teenager, good communication is vital.

- **Timing is key** – Sitting together without distractions or during joint tasks such as cooking or walking
- **Mood matters** – Discuss issues when the situation is calm and you both can think rationally
- **Prioritise discussions** – deal with those which are most concerning first rather than every small issue²

It may help to show them the 'How to look after a child with diabetes' information leaflet supplied in this pack.



Travelling and holidays

There is no reason why your child's diabetes should stop you from going on family holidays, they just require a bit more planning.

You may want to consider the following before going away:²

- Talk to your healthcare professional before you go about how to manage your child's diabetes, particularly if you are travelling to a different time zone
- If you are flying, you should take a letter from your healthcare professional regarding their medication and devices in your hand luggage
- Check you have enough insulin for the entire stay in advance, so you have time to order it if needed
- Does your accommodation have refrigeration to store insulin (if travelling to a hot climate)?
- Do you have the appropriate travel insurance?
- Does your child require any vaccinations or malaria tablets?
- Ensure you have supplies of glucose tablets, sweets or fruit juice for the journey in case of a hypoglycaemic episode
- It is a good idea to take a spare insulin pen (if you use these for injections) and blood glucose meter, as well as sufficient supplies of test strips, lancets and injection needles
- Make sure you are aware of how to manage sick days in case they become dehydrated or sick while you are away (refer to 'What to do on a sick day' leaflet for more information)

Diabetes affects siblings as well

A diagnosis of diabetes is not just limited to the child involved; it really impacts the whole family. As parents, you may need to spend extra time with your child as there is a lot to deal with when taking on a diabetes diagnosis, especially at the beginning.^{2,8}

Your child may feel alone, different, frustrated or scared about the future and understandably, will receive a lot of care and attention from you. If you have more than one child, diabetes care may cause some tension in the family.²

It is important to balance your time to minimise the impact diabetes will have on your relationship with your other child or children, as well the relationship between siblings.^{8,9}

Sibling rivalry

Balancing time between siblings may be difficult as a child with diabetes usually needs extra care and attention.^{2,9}

Ask your other children how they feel?

Their siblings may feel ignored, unimportant or forgotten. Some feel scared for their sibling's future or are worried about their own risk of getting diabetes. They may feel guilty because they did not develop diabetes, or blame themselves for giving their sibling sugary foods in the past. Favouritism could also play a role and siblings could feel a sense of jealousy for the attention from their parents and other close contacts.^{2,9}

Do they feel like they aren't getting the same attention as they used to?

Siblings could also give too much attention to their brother or sister with diabetes. The child could feel overwhelmed or believe they are being constantly watched. On the other hand, your child with diabetes may be jealous of their brothers or sisters as they perceive them to have more freedom and opportunities.⁹

It is therefore very important for siblings to be part of this adjustment and the best way to deal with diabetes is to treat it openly and discuss it as a family.

Explain what diabetes is to your children and what it means on a day-to-day basis for their sibling. Make sure you tailor this specifically to each child depending on their age and level of understanding.⁹ Try to involve them in their care too, such as clinic visits, so they are not excluded.



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Family time is precious so how can you manage it well?

There are a number of ways to help manage the sibling relationship after a diagnosis of diabetes. There are no right or wrong answers and it might be worth speaking to other parents in the same situation, through support groups or forums, for advice on this topic.⁸ Ask your healthcare professional about local support groups.

- Make sure you have one-to-one time for each child, respecting their unique interests needs and abilities^{8,9}
- Don't let diabetes-related conversations dominate but make an effort to broaden the topics to include areas of interest for the whole family^{8,9}
- Ensure that any treats or benefits that your child with diabetes receives match those of their siblings so they don't feel left out
- Encourage your children to tell you their thoughts and feelings and listen to what they have to say^{8,10}
- Make sure your children understand it is not the fault of their sibling and they are not to blame if they haven't received much attention recently
- Siblings may naturally look out for each other but try not to give them too much responsibility with managing diabetes. Ask if you need help but be cautious about making it a routine task as it can be stressful, even for teenagers^{8,10}
- Make sure the whole family eats the same healthy, well balanced meals⁹
- Try not to be too overprotective, kids are still kids and they will play, argue and compete with each other, diabetes does not change that⁸



The future

If their diabetes is managed effectively, children with diabetes can lead full and active lives.^{2,3}

Diabetes monitoring and treatment will become part of their daily lives, but should not limit their activities.^{2,3}

It is important that your child maintains the insulin schedule specified by their healthcare professional and regularly checks their blood glucose levels to maintain good control. A healthy diet and regular exercise will also help minimise the risk of developing complications in the future.^{2,3,6}

Your child's healthcare professional will be looking out for signs of any complications when they have their routine check ups, so they can be recognised early and managed appropriately. It is important that you and your child attend all scheduled appointments and ask any questions if you have any concerns.

As diabetes is a lifelong condition, there will be different aspects in approach to management at each stage of life. From recently diagnosed, through to school, university or work-life, you and your child will have access to support every step of the way.²

References

1. Silverstein J *et al.* Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care* 2005; 28: 186–212.
2. Diabetes UK. Children and diabetes. Available at: www.diabetes.org.uk/Information-for-parents/Living-with-diabetes-new/School/ Accessed July 2012.
3. NIH Medline Plus Library. Diabetes. Available at: www.nlm.nih.gov/medlineplus/ency/article/001214.htm Accessed July 2012.
4. Smart C *et al.* ISPAD Clinical Practice Consensus Guidelines 2009 Compendium: Nutritional management in children and adolescents with diabetes. *Pediatr Diabetes* 2009; 10(Suppl. 12): 100–117.
5. Robertson K *et al.* ISPAD Clinical Practice Consensus Guidelines 2009 Compendium: Exercise in children and adolescents with diabetes. *Pediatr Diabetes* 2009; Suppl 12: 154–168.
6. NICE Clinical Guideline 15. Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults. July 2004. Available at: www.nice.org.uk/guidance/CG15 Accessed July 2012.
7. Rewers M *et al.* ISPAD Clinical Practice Consensus Guidelines 2009 Compendium: Assessment and monitoring of glycemic control in children and adolescents with diabetes. *Pediatr Diabetes* 2009; 10(Suppl. 12): 71–81.
8. American Diabetes Association. Diabetes care at school. Available at: www.diabetes.org/assets/pdfs/schools/solutions-for-common-diabetes-mgmt.pdf Accessed July 2012.
9. Australian Diabetics Council. Teachers and schools. Available at: www.diabeteskidsandteens.com.au/teachers_and_schools.html Accessed July 2012.
10. American Diabetes Association. Position statement: Care of children with diabetes in the school and day care setting. *Diabetes Care* 2003; 26(Suppl 1): S131–S135.
11. Novo Nordisk website. Available at: www.novonordisk.com Accessed July 2012.

About Novo Nordisk

This information was developed by Novo Nordisk, a global healthcare company specialising in the care of people with diabetes.

Novo Nordisk was started up almost 90 years ago by a Danish couple with a passion for changing diabetes. August Krogh was a professor at the University of Copenhagen and Nobel Prize winner and his wife Marie, a doctor and researcher into metabolic diseases, suffered from type 2 diabetes. They learned of insulin being developed in Canada and were determined to ensure access to insulin for everyone with diabetes, hence in 1923 Novo Nordisk was born.

Since then Novo Nordisk has grown to become a world leader in the provision of diabetes products and support for patients of all ages.¹¹

We fully understand the challenges that children with diabetes face and are working together with parents, schools and healthcare professionals to improve the care of children with diabetes, as they grow up and develop.

For more information about Novo Nordisk, please visit: www.novonordisk.com



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