

TYPE 1 ESSENTIALS

for children and
young people

DiABETES UK
CARE. CONNECT. CAMPAIGN.



Living with diabetes is a challenge for any child – and their parents. Your family will need help to cope with this challenge – at school, at play, and on the journey to adult life.

This guide tells you as a parent the ten things you should expect from your child's diabetes care, to make sure you and your child can get on and enjoy life.

It includes the care, checks and help your child may need, to make sure their treatment is on track and their condition is managed well. It also sets out the support your child should get at school, in hospital and in wider society.

Use this guide to check if you and your family are getting everything you should. If there's something here you're not getting, take this guide along to your next appointment with your diabetes healthcare team and discuss it with them.

1 **Care from a specialist team**

Your children's diabetes team should be able to give you:

- treatment
- advice about food choices
- advice about eating healthily and keeping active
- support and advice to help with feelings or worries.



Your team should include:

- a **consultant** with experience in diabetes care for children
- a **children's nurse** with experience in diabetes
- a **dietitian** with experience in children's diabetes, who can advise you about **food choices**
- someone who can help you and your child **get advice about feelings** or worries.



2 **Regular checks**

All children should get:

- a **blood test** to measure their diabetes management (known as HbA1C) – four times a year
- regular checks of **weight, height** and **general health**
- screening for other conditions that are linked to diabetes – these include **coeliac disease** (when diabetes is diagnosed) and **thyroid disease** (when diabetes is diagnosed and then once a year)
- an opportunity to **agree goals**
- an opportunity to **talk about emotions** or things you might be struggling with.

Children age 12+ should also get:

- blood and urine** tests to check kidneys – once a year
- digital photo of **retinas (eyes)** – once a year
- blood pressure** check – once a year
- foot examination and **foot care** review – once a year.



3 The right treatments

You should be told about all the available treatments, including new ones. And you should be able to get the treatments that are right for your child. These **might** include:

- multiple daily injections, carbohydrate counting** and the most appropriate **insulin**
- blood glucose** and **ketone meters** and testing **strips**
- insulin pumps**
- continuous** blood glucose monitoring.



4 **Support so you can do it yourself**

As much as possible, your family should be able to manage your child's condition yourselves. To help you do this, you should be able to **get expert advice, education and information** that's easy to understand. This should include:

- consistent, **high-quality information** in a format that suits you and your child
- 24 hour access to **help and advice**
- education so your child can **learn how to manage their condition**
- advice on **eating well** and **keeping active**
- a **key contact** for you in your healthcare team
- the chance to regularly see a dietitian, who can advise you about **food choices**.

Your child may also be able to get Disability Living Allowance. For more information please visit www.gov.uk/dla-disability-living-allowance-benefit.



5 **Help with feelings or worries**

Coping with diabetes can be really difficult sometimes – for the child and for the rest of the family. It's perfectly normal to feel upset, angry, confused or worried. Make sure you **talk to your diabetes team** about this.

As part of your diabetes healthcare, your team should offer your child and your family the chance to talk to a psychologist – an expert in mental and **emotional health**.

They should have experience in diabetes and how it affects children and their families. You should be able to talk to them about particular issues if you need to, and have regular meetings just to see how things are going.



6 **The right care when you're in hospital**

If your child has to go into hospital for any reason, you should have contact with a children's diabetes team. You and your child should also be allowed to carry on managing their condition yourselves if possible. This will help the hospital staff to look after your child in the right way.



7 **A smooth transition to adult diabetes services**

Moving from child to adult healthcare services is a big change. It can be a difficult time for teenagers, who are already dealing with other changes in their lives. But it's important that the move works well, so children keep on getting the care they need.

The **two diabetes services should work together** to make sure the move goes as smoothly as possible for your child, at an age that's right for them, and in a way that suits them.



8 **A say in the care you get**

You and your child should be involved in making decisions about the care you get, and have a say in how your child's diabetes is managed. For example, you should:

- be able to **work with your doctor or healthcare team** to create a plan for how your child's diabetes will be treated and managed, talk through the plan, and ask any questions
- get **copies of letters** that say what everyone's agreed
- help design services that are **right for you**.

You should also be invited to fill in a national Patient Reported Experience Measure survey. This collects information about the kind of care children with diabetes are getting.



9 Support at school

Your child should have all the support they need to do well at school. They **should be able to take part in all areas of school life**, including classroom work, trips, sports and after-school clubs.

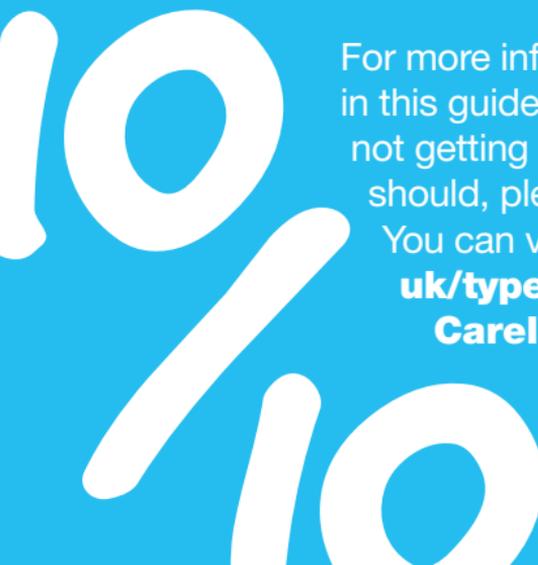


Your diabetes team should work with your school to make sure that happens. For example, they should:

- agree a healthcare plan** with you and your child
- work out who will make sure your child gets the diabetes care they need at school
- keep plans up to date and make sure everyone knows what's happening.

10 **Equal opportunities**

Your child should be given the same opportunities as everyone else, and not be treated differently simply because they have diabetes. They should be able to join in with sports, activities, clubs and groups. And they should be able to learn to drive and do most jobs.



For more information about what's in this guide, or what to do if you're not getting the care and support you should, please contact us.

You can visit **www.diabetes.org.uk/type-1-essentials** or call our **Careline** on **0845 120 2960**.

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