

WHAT CARE TO EXPECT IF YOU HAVE TYPE 1 DIABETES



DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

About this leaflet

Everyone with type 1 diabetes should get certain checks and tests from their healthcare team to help them live well with diabetes.

There are some checks that everybody living with type 1 diabetes should have. There are others that not everyone needs or that you may only need at certain times.

This leaflet will help you to:

- Understand what help you should be able to get when you need it.
- Know what checks you should have regularly.
- Make a checklist of what you've already had and still need.
- Make notes about what you want to discuss with your healthcare team that you can bring to your appointments.

MAKING THE MOST OF YOUR APPOINTMENTS

Everybody living with type 1 diabetes should be able to have good quality conversations with their healthcare team, where you can discuss your individual needs and progress.

Before you go to your appointments, think about:

- Which areas of your diabetes care you would like to focus on. Perhaps take a list of three bullet points with you that you want to discuss.
- Anything that's worrying you about your diabetes.
- Whether your diabetes is affecting your general wellbeing and what help you might need.
- Whether you've read anything, or seen anything online that you want to discuss, like new research or a particular type of diabetes tech.

Your healthcare team might give or send you a form for blood tests or other tests you need before your appointment. It's helpful to have your test results ready to talk about at your appointment, so try to have them done at least a week before.

During the appointment:

- Remember that your healthcare team should always be led by your needs.
- If your questions aren't being answered, don't be afraid to ask again and bring the conversation back to what you want to discuss.
- If it feels like it's all about your diabetes numbers, try asking if you can discuss how diabetes is affecting your life and not just your blood sugars.
- At the end of your appointment, agree a clear plan of action, including how long it should be until your next appointment.

Remember, you can ask for another appointment, or a referral to a diabetes nurse or dietitian if you want to.

CARE TO EXPECT WHEN YOU'RE FIRST DIAGNOSED

When you were diagnosed with type 1 diabetes, you should have had the following conversations and checks with your healthcare team in the first six months. Tick off what you've already had and if there's anything missing, ask your healthcare team if you still need them:

- A full assessment of your medical history, and anything going on in your personal life that might affect your diabetes.
- An individual diabetes management plan, discussed and agreed on with your healthcare team, that works for you and your cultural background, including your personal targets, contact details for your diabetes team and follow-up plans.
- Detailed information on how to live well with type 1 diabetes including giving your insulin, counting carbohydrates, managing hypos, managing when you're ill, physical activity, and rules about driving licenses.
- A review with a dietitian.
- Within a year of diagnosis, a referral to a diabetes group education programme that works for you and your cultural background, or the same type of education in a one-to-one appointment if you prefer.
- Information about the medical exemption form for free prescriptions if you live in England. You don't need this in Northern Ireland, Scotland, and Wales as prescriptions are free for everyone.
- Your antibodies measured to confirm your diagnosis if it's not clear what type of diabetes you have.

REGULAR CARE TO EXPECT

Everyone with type 1 diabetes should have the following checks and appointments at least once a year. Tick off what you've already had and ask your healthcare team about when you'll have anything that's missing:

- An HbA1c test, which checks your average blood glucose levels over the last three months.
- A review of your weight and BMI.
- A blood pressure check, a cholesterol test to check your blood fats, and blood and urine tests to check how well your kidneys are working.
- An eye screening appointment to check for signs of diabetic retinopathy, which is a complication of diabetes. But this might be every other year if your previous checks were fine.
- A foot check to make sure you don't have problems with nerves or blood supply in your feet. This may be once every other year if you live in Scotland and are at low risk of foot problems.



CARE TO EXPECT IF YOU NEED IT

Everyone with type 1 diabetes should also have access to other help if you need it. But diabetes clinics can work differently in different places, so talk to your diabetes team if you need this help but are not getting it:

- An HbA1c check every three to six months if you are struggling to meet your agreed targets.
- A review of your medical history and anything in your personal life that might affect your diabetes.
- A review and update of your management plan.
- A review of the diabetes knowledge you already have and would like to have.
- Advice about your diet from a dietitian.
- A review of your emotional wellbeing and mental health needs.
- A thyroid function blood test.
- Pre-pregnancy review if you're planning to have a baby, and advice from specialists at least 12 weeks before stopping contraception.
- Regular reviews at least every two weeks by the diabetes team during pregnancy.
- Good quality care with access to diabetes specialists if you are in hospital, including access to mental health support if needed.
- A chat about the diabetes technology offered locally that could help you. This includes continuous or flash glucose monitoring, which everyone should have access to if they would like it, or an insulin pump if you are not meeting your targets.
- Support with sexual health concerns.

- Access to the right specialists to help you manage complications, like referral to an ophthalmologist (an eye doctor) if you have eye complications.
- The chance to meet and get support from others with type 1 diabetes.
- Access to diabetes specialists who can help you manage your medication and blood sugars around physical activity.
- Appointments in a way that you prefer, whether that's phone or video appointments, review of your blood sugar levels online, or face-to-face appointments.

You will also have access to other NHS care that is still important for your diabetes management, like flu and Covid-19 vaccines, screening services for other conditions, help to give up smoking, weight management support, and dental care.

Some areas also offer other opportunities to improve your general health and diabetes wellbeing, like organised physical activity, weight management groups and other active community groups. Ask your healthcare team what other support is available to you.



WHAT IF I'M NOT GETTING THE CARE I NEED?

Sometimes it might be difficult to get the standard of care you should expect. If you don't think you are getting the checks you should be, speak to your healthcare team. You could take this leaflet with you and use it to help you ask about specific checks or types of support.

If that does not help you, you may want to make a complaint. You can find out more at diabetes.org.uk/care-complaints

If you're still not happy with the care you're getting, you can ask for your diabetes care to happen at a different clinic or hospital. You can find out more by speaking to your GP or calling our helpline on **0345 123 2399**.





GET IN TOUCH

Call **0345 123 2399**

Email **helpline@diabetes.org.uk**

Visit **diabetes.org.uk**

Search **Diabetes UK** on Facebook, Twitter, YouTube, Instagram and TikTok



We welcome your feedback. If any information in this guide has been particularly helpful or if you would like to suggest any improvements, please send your comments to: **helpline@diabetes.org.uk** or write to us at: Diabetes UK Helpline, Wells Lawrence House, 126 Back Church Lane, London E1 1FH

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