

Get the test strips you need advocacy pack

This pack will help you challenge any decisions
to restrict your test strips on prescription.



Reviewed: March 2017

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

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Introduction

A lot of people have contacted us because they've had the amount of test strips they can get on prescription reduced or even stopped altogether.

The decision to reduce your test strips may have been taken as a cost saving exercise by your local NHS, Clinical Commissioning Groups (CCG) in England, Health Boards in Scotland and Wales, or Health and Social Care Trust in Northern Ireland.

In the NHS testing your blood glucose levels (or sugar levels) is often called self-monitoring of blood glucose (SMBG). In this pack when we talk about testing this is what we're referring to.

What we think about the restriction of blood glucose test strips

Testing is an essential part of care for people using insulin

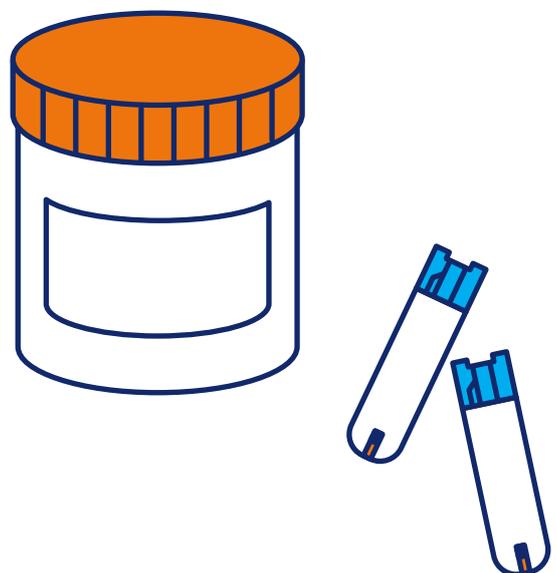
The last 20 years have shown that tightly controlled blood glucose levels (also called blood sugar levels) are linked with a significant reduction in serious long-term, diabetes-related complications.

For anyone with diabetes who uses insulin regular testing is a vital tool in keeping good control of blood sugar levels. For people with Type 1 diabetes there is clear evidence that testing, together with a range of interventions, improves long-term control of blood glucose levels¹. It's also widely recognised that testing, when supported by education, is beneficial for all people with Type 1 diabetes². Along with helping people achieve tighter blood glucose levels, testing means they can spot and treat low blood glucose levels before they suffer severe hypos.

Testing for people with Type 2 who don't use insulin

The exact role of testing for people with Type 2 diabetes who are not on insulin is less clear. However many people with Type 2 diabetes, and many of the healthcare professionals that support them, recognise that testing helps people to self-manage their diabetes and that there are significant quality of life and patient satisfaction benefits.

People with Type 2 diabetes who are treated with sulphonylurea and prandial glucose regulators will need to test because they can cause hypos. Other people with Type 2 diabetes should talk to their GP or healthcare team and make a joint decision about how many test strips are needed (if they are).



What the government says

In England the Department of Health has given guidance to healthcare professionals, pharmacists and NHS managers around test strips for people with Type 1 diabetes.

In a letter sent in 2013 the Department of Health was made clear that being able to test is essential for people with Type 1 diabetes in order to carry out their daily lives³.

“ Their lives depend on insulin injection or pump treatment. They carry out self-blood glucose measurement (SBGM) on finger-prick tests to adjust their insulin dosage according to food, exercise, and other daily events. SBGM is essential for safety checks when feeling unwell, or in situations when the blood glucose might fall too low or too high...In summary, it is essential that people with Type 1 diabetes are prescribed sufficient SBGM testing strips for their clinical needs...This enables people with diabetes to self-manage, including understanding ‘sick day rules’, recognising the symptoms of DKA, early action and how to seek help, and any specific considerations in light of any job they may carry out, especially if it involves driving. ”

You can send this letter to your GP, hospital doctor, community pharmacist and Clinical Commissioning Group (your local CCG manages the NHS in your area) to make sure that they're aware of and keeping to the guidance.

If you live in Scotland, Wales or Northern Ireland the letter still might be helpful when you're arguing your case.

You can find the full letter online at:
www.gov.uk/government/publications/importance-of-finger-prick-tests-in-managing-type-1-diabetes

In Northern Ireland, the Health and Social Care Board have released regional guidance on what they call the self-monitoring of blood glucose (SMBG) for people with Type 2 diabetes. This guidance is being reviewed but more information can be found here:

<http://niformulary.hscni.net/Formulary/Adult/6.0/6.1/6.1.6/Pages/default.aspx>



What can I do if my test strips have been restricted?

First, contact your GP and find out why the decision to stop or reduce your test strips has been made. You'll need to find out if it's because your healthcare team have made a decision based on your personal circumstances, or if it's because of a blanket restriction made by your local NHS that does not take into account your individual needs.

How can a Medicines Use Review help?

As someone with a long-term condition like diabetes you're allowed a Medicines Use Review. This is a free NHS service offered by pharmacists across the UK to help you get the best out of your medicines. In your review you can talk about any restriction of test strips you're facing and how this affects your diabetes management. The pharmacist will fill in a form called a Medicines Use Review action plan so that you have a record of what was agreed, and a copy will go to your GP. This report should make clear the difficulties you're facing in getting enough test strips and recommend an increase in the amount prescribed.

You can find out more about Medicine Use Reviews at:
<http://psnc.org.uk/services-commissioning/advanced-services/murs/murs-the-basics>

What should I do if my healthcare team reduced my strips because they don't think I need them?

Any decision made about your need for test strips should be made between you and your GP or healthcare team. If you weren't involved in the decision then you will need to make a case for why you need to continue testing and the number of times you need to test. This should include details of how you use your test results and what actions you take based on them.

This issue can only be solved through talking with your GP or healthcare team and may depend on the individual case you make for testing. If they continue to restrict your test strips, it is important you meet with your GP or healthcare team to discuss the decision. Make sure you fully understand why this decision has been made. If your GP or healthcare team feels that your current testing is not effective and you are not acting on the results appropriately, you can ask for help to learn how to better monitor your blood glucose levels.

What do I do if my local NHS has set a restrictive policy?

If the number of test strips you're being prescribed is restricted because of a formal policy across your whole area, contact your local CCG requesting a copy of the policy. It may have been produced as guidance and should explain why this decision was made.

Don't take for granted that your surgery manager or GP are following guidelines correctly. Ask your GP for their understanding of the guidelines and request to see any information they have on this subject. If you feel your surgery is being too rigid in their understanding of such guidance you can challenge it. Put forward your interpretations and attempt to reach an agreement with your GP or healthcare team.

How do I make my case for testing?

When making your case for getting the test strips you need you will have to explain how and why testing your blood glucose levels helps you to look after your diabetes. Some of the most common reasons are below. Choose what is relevant to you based on the type of diabetes you have, the treatment(s) you use, and the particular problems you are experiencing in accessing test strips at the moment. Make sure you explain these points in full to stress the benefit that testing is giving you, and the impact any restriction is having. Our Helpline can support you to do this.

- Explain if you are at risk of hypos, ketoacidosis or hyperglycaemia.
- If you drive and your diabetes medication could cause you to experience hypos
- If you carbohydrate count
- If you want to improve blood glucose levels prior to trying for a baby
- If you are breast feeding
- If you want to improve control during pregnancy
- If you're very active and regularly take part in intensive physical activity such as running, swimming, or gardening
- If you have a job that requires pro-active self-management, particularly to avoid hypos
- If you live alone
- If you are at an increased risk of falls
- Suspected or confirmed unawareness of hypos
- Look at the records of your HbA1c results over a period of time (your last four results at least). If your results were outside the target range of 48 mmol/l or below, say how you use your test strips to support your self-management to improve your control. If your HbA1c is within the target range you need to stress how you use your test results to achieve and maintain this. It is important that people with diabetes are taught how and when to use blood glucose tests and how to use the results as part of managing their condition. You can find information on blood glucose targets: www.diabetes.org.uk/Guide-to-diabetes/Managing-your-diabetes/Testing

Further help

We have more information that will support your case in our two position statements on testing.

- Self-monitoring of blood glucose for people with Type 1 diabetes
www.diabetes.org.uk/position-smbg
- Self monitoring of blood glucose for adults with Type 2 diabetes
www.diabetes.org.uk/position-smbgt2

Other useful information to help you make your case

- The National Service Framework for Diabetes (NSF), published in 2001, focuses on making sure that people with diabetes are able to increase their control of their day-to-day management of their diabetes. They say testing is an appropriate means of supporting self-management for some people. You can read the NSF at www.gov.uk/government/publications/national-service-framework-diabetes
- NICE, who make clear what care people should get on the NHS, has published a quality standard for diabetes which provides an authoritative definition of good quality care. www.nice.org.uk/guidance/qs6
- NICE has produced guidance on testing for people with Type 2 diabetes which highlights the role of blood glucose monitoring as part of supporting people to manage their condition themselves. This guidance, Type 2 Diabetes In Adults: Management, can be found at www.nice.org.uk/guidance/NG28



What can I do if I am unhappy with the response I receive?

If you are not satisfied with the response you receive about getting the test strips you need you have the right to complain and have your complaint investigated. Anyone who provides care on the NHS must have a complaints procedure. They must publicise their procedure and give clear information about how to make a complaint. Ask a member of staff for details, look on the surgery, hospital or CCG's website or contact their complaints department for a copy of the complaints procedure.

A complaint can be made verbally or in writing, including email. It is useful if your complaint is in writing. You should make it clear that you wish the complaint to be investigated under the NHS complaints procedure and include the following information:

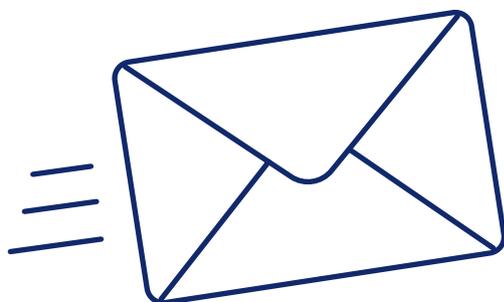
- Full details of the matter you are complaining about
- What you would like to see as a result of the complaint, eg an explanation, apology or change to the system.

Keep copies of all letters sent and received and send photocopies, not originals, of any documents you are including. You should expect an acknowledgement letter in two to three working days. If your complaint is regarding primary care (about your GP, or surgery), you should receive a full response within 10 working days. If it is about secondary care (hospital) you should hear back within 25 working days. If your complaint is going to take longer you should be kept informed.

You may also like to raise the issue with your MP. You can find out who your MPs at www.parliament.uk/mps-lords-and-offices/mps

You may want to include a copy of our position statements on testing, with your letter or email.

- Self-monitoring of blood glucose for people with Type 1 diabetes
www.diabetes.org.uk/position-smbg
- Self monitoring of blood glucose for adults with Type 2 diabetes
www.diabetes.org.uk/position-smbgt2



Who can help me complain?



In England

The Patient Advice and Liaison Service (PALS).

PALS offer confidential advice, support and information on health-related matters to patients, their families, and their carers. They can help with health-related questions and with resolving concerns or problems when using the NHS. This includes giving information about the NHS complaints procedure and how to get independent help if you want to make a complaint. You can ask your GP surgery or hospital for details of your nearest PALS, search on NHS Choices or phone NHS 111 if available in your area.

Web: [www.nhs.uk/Service-Search/Patient%20advice%20and%20liaison%20services%20\(PALS\)/LocationSearch/363](http://www.nhs.uk/Service-Search/Patient%20advice%20and%20liaison%20services%20(PALS)/LocationSearch/363)

Local HealthWatch

This is the new 'consumer champion' for both health and social care. In some areas, local HealthWatch organisations will just be able to give general advice and support about complaints about the NHS. In other areas, they will be able to put your case across for you if you make a formal complaint.

Web: www.healthwatch.co.uk/find-local-healthwatch

Email: enquiries@healthwatch.co.uk

Call: 03000 683 000

NHS Complaints Advocacy Services

Local authorities have the responsibility for commissioning independent NHS Complaints Advocacy services. These replace the former Independent Complaints Advocacy Service (ICAS) service which helped people wishing to make a formal complaint about an NHS practitioner or service. In some areas, local HealthWatch will carry out these services. In other areas, local authorities may group together to commission the service at a regional level. For more information on the NHS Complaints Advocacy service in your area, contact your local PALS or Healthwatch.

Parliamentary and Health Service Ombudsman (PHSO)

The PHSO make final decisions on complaints that have not been resolved by the NHS in England and UK government departments and other public organisations.

Address: The Parliamentary and Health Service Ombudsman, Millbank Tower, Millbank, London SW1P 4QP.

Web: www.ombudsman.org.uk

Email: phso.enquiries@ombudsman.org.uk

Call: 0345 015 4033 (Complaints helpline)



In Scotland

The Patient Advice and Support Service (PASS).

PASS is part of the Scottish Citizen's Advice Bureau (CAB) Service and provides free confidential information, advice and support to anyone who uses the NHS in Scotland. PASS can provide information on rights and can help people to make comments and complaints about the care provided by the NHS in Scotland.

Web: www.patientadvicescotland.org.uk

Scottish Public Services Ombudsman (SPSO)

The SPSO is the final stage for complaints about the NHS in Scotland. To make a complaint to the SPSO you must fill in a complaint form. You can do this online or you can order a paper form by phone.

Address: SPSO, Freepost EH641, Edinburgh EH3 0BR.

Web: www.spsso.org.uk

Call: 0800 377 7330 (Advice line)



In Wales

Community Health Councils (CHCs)

CHCs are independent organisations which provide help and advice if you have problems with or complaints about NHS services. Each CHC has a complaints advocacy service to assist with individual complaints.

Web: www.wales.nhs.uk/sitesplus/899/home

Email: enquiries@waleschc.org.uk

Call: 02920 235 558

Public Services Ombudsman for Wales (PSOfW)

The PSOfW is the organisation that looks into complaints about the health service and other public bodies in Wales.

Address: Public Services Ombudsman for Wales,
1 Ffordd yr Hen Gae, Pencoed CF35 5LJ.

Web: www.ombudsman-wales.org.uk

Email: ask@ombudsman-wales.org.uk

Call: 0300 790 0203



In Northern Ireland

The Patient and Client Council

The Council provides free and confidential advice, information and help to make a complaint.

Web: www.patientclientcouncil.hscni.net

Email: info.pcc@hscni.net

Call: 0800 917 0222

Northern Ireland Public Services Ombudsman (NIPSO)

NIPSO reviews complaints about the health service in Northern Ireland fairly and independently.

Address: The Ombudsman, Freepost BEL 1478,
Belfast BT1 6BR.

Web: <https://nipso.org.uk/nipso>

Email: ombudsman@ni-ombudsman.org.uk

Call: 02890 233821 or 0800 34 34 24 (freephone)



Across the UK

The Citizens Advice Bureau (CAB)

The CAB can give you advice and information on making complaints, including how to find more help in putting across your case, for example. There are offices all across the UK and you can find your local office in the phone book or on their website.

Web: www.citizensadvice.org.uk

Web: www.adviceguide.org.uk (online advice)

Call England: 03444 111 444

Scotland: 0808 800 9060

Wales: 03444 77 20 20

Northern Ireland: 028 9023 1120

The Patients Association

The Patients Association advocates for better access to accurate and independent information for patients and the public. It fights for equal access to high quality healthcare for patients and the right for patients to be involved in all aspects of decision making regarding their healthcare. They have a helpline for concerns and queries about any aspect of the healthcare system.

Web: www.patients-association.org.uk

Email: helpline@patients-association.com

Call: 0845 608 4455 or 020 8423 9111

What we're doing about test strips

We're fighting to make sure everyone with diabetes gets the test strips they need to manage their condition well.

We've constantly reminded national governments and NHS managers that access to test strips should be based on each person's need. Where we have found areas which restrict access to test strips we have campaigned for them to change their policy.

We've also raised the issue of test strip restrictions at the All Party Parliamentary Group for Diabetes, which we help support. The groups report published earlier in the year (LINK) made clear the impact restrictions are having on people with diabetes.

Thanks to people with diabetes taking part in our test strips survey we've been able to show just how many people are affected by restrictions and the effect it has on their lives.

Our volunteer campaigners Diabetes Voices fight with us for the best possible care for everyone with diabetes across the UK. And they've been raising the issue of test strips in their local area. You can join them and become a Diabetes Voices member.

Web: www.diabetes.org.uk/voices

Email: diabetesvoices@diabetes.org.uk

Call: 0345 123 2399*



References

- 1 Development and progression of long term complications in insulin dependent diabetes. N Eng J med. 1993;329:977-986
- 2 NICE. Type 1 diabetes in Adults: diagnosis and management. Clinical guideline NG17
- 3 www.gov.uk/government/uploads/system/uploads/attachment_data/file/141448/Safe-care-of-people-with-type-1-diabetes.pdf

How else we can help you

Call our helpline

Our Helpline is staffed by trained counsellors who really know diabetes. They can help you with information about diabetes, take the time to talk things through and explore any emotional, social, psychological or practical difficulties. For more information and support about your rights and how to get on a diabetes education course they're the people to call.

Call: 0345 123 2399*

Monday to Friday, 9am–7pm*

Email: helpline@diabetes.org.uk

Web: www.diabetes.org.uk/helpline

If you're in Scotland

Call: 0141 212 8710*

Monday to Friday, 9am–7pm.

Email: helpline.scotland@diabetes.org.uk

Join our online communities

Our online Support Forum and Facebook and Twitter communities are a great place to meet other people with diabetes. Morning, noon and night you'll find loads of people sharing their experiences, offering each other support offering plenty of advice about life with diabetes.

Web: forum.diabetes.org.uk

Join a local support group

The members of our 380 support groups up and down the UK have been there, down that and got the Diabetes UK t-shirt. They normally meet once a month to share experiences, offer support and learn more about diabetes. Find your local group on our website.

Web: www.diabetes.org.uk/groups

Call: 0345 123 2399*

Type 2 Diabetes and Me

Our free interactive online tool helps people with Type 2 diabetes understand and manage their condition well. It gives people the chance to learn what they want when they want. It was developed by Diabetes UK, in partnership with Bupa.

Web: www.type2diabetesandme.co.uk

Type 1 Events

Our events for children, teenagers, adults and families have run for over 80 years and are designed to make sure diabetes holds no one back. The events are about sharing experiences, building confidence and creating more freedom to live with diabetes.

Web: www.diabetes.org.uk/type-1-events

Join Diabetes Voices

Diabetes Voices are members of the public who campaign with us to improvements in diabetes services and care across the UK. If you would like to become a Diabetes Voice, or for more information, get in touch.

Web: www.diabetes.org.uk/voices

Email: diabetesvoices@diabetes.org.uk

Call: 0345 123 2399*

For help making a complaint

If you're unhappy with any of the care you've received we've got all the information and advice you'll need on our website in our **Making a complaint about healthcare advocacy pack**.

Call: 0345 123 2399* (ask to have the pack sent out to you).

Find out more on our website

We've got loads of free information, advice, tips and guides on our website to help you live well with diabetes. If you prefer you can also order printed magazines and information leaflets from our online shop.

Web: www.diabetes.org.uk

Web: shop.diabetes.org.uk

Call: 0345 123 2399*

The information in this pack shouldn't be considered a complete guide to the law, which can change from time to time. Legal advice should always be taken if you've got any doubts. We're not able to give legal advice.

Advocacy pack feedback form

You can help us improve our advocacy packs by telling us what you think of this Get the test strips you need pack.

Once you've filled it out you can send it to **Diabetes UK Freepost LON 12857** or email it to advocacy@diabetes.org.uk

1 How did you use this pack?

Personally, to help yourself Professionally, to help someone General information

2 How useful did you find this pack?

Very good Good OK Poor Very poor

3 What did you find most/least useful in the pack?

.....
.....
.....

4 Did the pack answer your questions? Yes No Partially

Can you give details?

.....
.....

5 What changes would you make to the pack?

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.....
.....

6 How did you hear about the pack?

Friend/relative Healthcare professional Diabetes UK Helpline
Website *Diabetes Balance* magazine
Other Please specify:

7 What other subjects would you like an advocacy pack on?

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.....

Thank you for taking the time to complete this form.