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Availability of blood glucose test strips

This pack has been produced for people with diabetes who are concerned about the restriction of blood glucose test strips on prescription.

It contains information about how to challenge any test strip issues and some tools to help you advocate for yourself.



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Introduction

Diabetes UK has been contacted by a lot of people with diabetes who have been refused prescription of blood glucose test strips or have had their prescription reduced.

The decision to reduce your test strips may have been taken as a cost saving exercise by your local healthcare provider, ie your Primary Care Trust (PCT) in England, Health Boards in Scotland and Wales and Health and Social Care Trust in Northern Ireland.

It has been shown that some people with diabetes do not always use test strips effectively to manage their diabetes and some healthcare providers are undertaking a review of their policies in relation to test strip prescription.

It may be useful to discuss this with your diabetes healthcare team to find out more information.

What does Diabetes UK think about the restriction of blood test strips?

Diabetes UK believes people with diabetes have the right to be prescribed the number of strips they need to be able to manage their diabetes. Your requirement will be decided in agreement with your diabetes healthcare team and should take into account your own personal circumstances, lifestyle, type of diabetes medication and self-management techniques. Your access to test strips should not be affected by your ability to pay or where you live and receive your care.

The decision to restrict blood glucose testing strips can fail to consider that people with diabetes self-manage their condition 95 per cent of the time. Self-monitoring, supported by education and training about what to do with test results, provides the information needed to make daily adjustments in order to maintain good diabetes control. Such adjustments may include altering the dose of your medication, delaying a meal, or taking exercise to counteract a high blood glucose reading, deciding when to eat to decrease the risk of hypoglycaemia (hypos) and deciding when to seek medical help. Testing enables people with diabetes to self-manage their condition and to track, and take action on, blood glucose patterns over a period of time. This supports self-management, thereby reducing the risk of complications over time (Diabetes Control and Complications Trial, 1993; UK Prospective Diabetes Study, 1998).

Research looked at by the National Institute of Clinical Excellence (NICE) (2008) added further evidence 'to the view that self-monitoring of blood glucose levels was an integral part of effective patient education packages and enabled effective use of many other therapies and lifestyle interventions'. Further 'The evidence that plasma glucose monitoring could be replaced by urine glucose monitoring was found to be poor'.

NICE recommendations

Self-monitoring of plasma glucose should be available:

- to those on insulin treatment
- to those on oral glucose lowering medications to provide information on hypoglycaemia
- to assess changes in glucose control resulting from medications and lifestyle changes
- to monitor changes during intercurrent illness
- to ensure safety during activities, including driving

Assess at least annually and in a structured way:

- self-monitoring skills
- the quality and appropriate frequency of testing
- the use made of the results obtained
- the impact on quality of life
- the continued benefit
- the equipment used



If self-monitoring is appropriate but blood glucose monitoring is unacceptable to the individual the use of urine monitoring should be discussed.

The importance of self-monitoring for the effective use of insulin therapy and for those at risk of hypoglycaemia through leisure or work activities (including driving) on oral medications was noted. The frequency of monitoring that is useful to someone with diabetes is highly individual and it is inappropriate to put an artificial restriction on this.

See page 8 for Diabetes UK's full position statement on blood glucose test strips. This is also available on the Diabetes UK website www.diabetes.org.uk/position-smbg or you can contact the Diabetes UK Careline 0845 120 2960 for a copy.

What can I do to challenge the restriction of my test strips?

In the first instance you should contact your GP and ask for clarification about why the decision to stop or reduce your test strips has been made. You will need to find out if this is a decision that your diabetes healthcare team has made based on your personal circumstances, or if it is because of a blanket restriction made by your healthcare provider that does not take into account your individual needs.

What do I do if my GP and/or diabetes healthcare team has reviewed my need for test strips based on individual need?

Any decision made about your need for test strips should have been reached in partnership with you. If the decision to stop or restrict the number of test strips prescribed to you has been made by your GP or healthcare team without you, 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 resolved through talking with your GP or healthcare team and depends on the individual case you make for testing. If the decision is still to stop or restrict the number of 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 home monitoring is not effective and you are not acting on the information appropriately you can ask for further education to help enable you to manage your monitoring.

What do I do if my healthcare provider has set a restrictive policy?

If your GP or other healthcare professional is restricting the number of test strips prescribed because of a formal restrictive policy across your whole area, write to your healthcare provider requesting a copy of the policy, which may have been produced as guidance, and details of how and why this decision was made. Don't take for granted that your surgery manager or GP are following guidelines in the intended way so 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 a mutual agreement.

How do I make my case for testing?

Several points are made below. You can choose those relevant to you based on the type of diabetes you have, the treatment(s) you use to manage your diabetes, and the particular problems you are experiencing in accessing test strips at the moment.

- Emphasise the action, or actions, you take after doing blood glucose tests and stress how using test strips is central to enhancing your self-management.
- Explain if you are at risk of hypos, ketoacidosis or hyperglycaemia.
- If you drive and your diabetes medication could cause you to experience hypoglycaemia
- If you are very active or lead an unpredictable lifestyle, eg shift work.



- Look at the records of your HbA1c results over a period of time (eg the last four results). If your results were outside the target range of 6.5% or below, say how you use your test strips to support your self-care 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 diabetes self-care. You can find information on blood glucose targets on our website at: www.diabetes.org.uk/glucose-targets or alternatively contact Diabetes UK Careline 0845 120 2960.
- The Service Frameworks for diabetes in the UK focus on making sure that people with diabetes are able to increase their personal control over day-to-day management of their diabetes. Home monitoring through blood and urine testing is an appropriate means of supporting self-management for some people. The National Service Frameworks are available online at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002951
- NICE has produced guidance on self-monitoring for people with Type 2 diabetes which highlights the role of blood glucose monitoring as part of an integrated self-management package. You can access this guidance via the NICE website at www.nice.org.uk or through the NHS response line on 0870 1555 455. Ask for *Type 2 Diabetes: the Management of Type 2 Diabetes (update)*, (reference number CG66)
- Diabetes UK produces a free leaflet called *Diabetes Care and You* that includes information about the need for self-monitoring and target ranges. This leaflet can be downloaded for free via our website www.diabetes.co.uk/onlineshop or ordered via our publication orderline 0800 585 088.

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

If you are not satisfied with the response you receive you have the right to complain and have your complaint investigated. All NHS healthcare providers and service providers, eg GP, dentists, opticians and pharmacists 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 or look on the surgery, hospital or trust's website or contact the complaints department for a copy of the relevant healthcare organisations 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 or apology or change to the system.

You may want to enclose a copy of Diabetes UK's position statement 'Self monitoring of blood glucose levels' with your letter. See page 8, or download from www.diabetes.org.uk/About_us/Our_Views/Position_statements/Self-monitoring_of_blood_glucose/Diabetes or you can contact the Diabetes UK Careline 0845 120 2960 for a copy. You may also like to contact your MP to discuss the issue.

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, eg GP and dentists, you should receive a full response within 10 working days and if it is regarding hospital/secondary care within 25 working days. If your complaint is going to take longer you should be kept informed.

For a basic letter format to send to your local healthcare provider, please see page 7. You can either use this letter as a basic framework for your own personal letter, or you can write your own letter and include this with it.



Who can help me complain?

In England

- The Patient Advice and Liaison Service (PALS). PALS can give you information and advice about how to complain. There is one in each trust and PCT.
- The Independent Complaints Advocacy Service (ICAS) are independent of the NHS and provide advice and support to patients and their carers wishing to pursue a complaint about their NHS treatment or care.

In Scotland

- Citizens Advice Bureaux in Scotland are funded by local NHS boards to deliver Independent Advice and Support Services (IASS) to support patients, their carers and relatives to raise concerns and make complaints.
- If you need an independent advocate to help you make your complaint, your local NHS board will be able to give information about this.

In Wales

- The Community Health Council (CHC) Wales. The Council provides free confidential help if you have a problem or complaint with NHS services in Wales. Each CHC has a complaints advocacy service to assist with individual complaints.

In Northern Ireland

- The Patient and Client Council. The Council provides free and confidential advice, information and help to make a complaint.
- The Citizen's Advice Bureau. Your local Citizen's Advice Bureau can provide advice and information on making complaints.

(See back of pack for relevant contact details).

What is Diabetes UK doing about this issue?

A number of steps need to be taken to identify the source of, and then influence, the decision made to restrict the number of test strips people with diabetes are being prescribed. Diabetes UK has written to all prescribing advisors of healthcare providers asking for a copy of any policies and reinforcing the position that access to strips with education should be on the basis of individual clinical need and informed choice. We have identified a number of areas with restrictive policies and have contacted them directly. We also alert 'Diabetes Voices' working with healthcare providers about issues as they arise.

When further research evidence is available Diabetes UK will submit this issue as a topic area to be reviewed by organisations providing national guidance. Diabetes UK is in the process of commissioning research to assess the benefit of blood glucose testing for people with Type 2 diabetes. We will keep people informed, through *Balance* and our website (www.diabetes.org.uk), as more information becomes available.

You may want to raise your voice and make a difference to diabetes services and care. You can find further information about joining Diabetes Voices and sign up at www.diabetes.org.uk/diabetesvoices or phone the Diabetes Voices team on 020 7424 1008.



Dear

Re: Availability of blood glucose test strips for people with Type 1 and Type 2 diabetes

It has been brought to the attention of Diabetes UK that some healthcare providers are imposing blanket restrictions on the number of blood glucose testing strips they are allowing GP practices to prescribe their patients.

We would like to see each individual's requirement for blood glucose test strips decided in agreement with their diabetes care team and for this requirement to take into account the individual's personal circumstances, lifestyle, type of diabetes medication and self-management techniques. Decisions to restrict blood glucose testing strips often fail to consider that people with diabetes self manage their condition 95 per cent of the time, with advice and support from their healthcare professionals. With appropriate education and training about what to do with test results, self-monitoring can provide the information patients need to make daily adjustments in order to maintain good diabetes control. This supports self-management, thereby reducing the risk of complications over time (Diabetes Control and Complications Trial, 1993; UK Prospective Diabetes Study, 1998).

The long-term cost savings to be made from supporting self management are of course considerable, both in reducing the frequency of support needed from the NHS and by preventing people with diabetes from needing hospital treatment due to diabetes emergencies or long-term complications.

Diabetes UK strongly believes that people with diabetes should have access to home blood glucose monitoring based on their individual clinical need and not on their or the NHS's ability to pay. Home monitoring is essential (within the context of diabetes education for self-management) in order to enable each person to make appropriate treatment or lifestyle choices.

There is no national decision to restrict blood testing strips and restriction or refusal to supply is a local level decision. Any healthcare provider which is automatically discouraging the prescription of blood glucose testing strips is not acting in accordance with NICE (National Institute for Health and Clinical Excellence) advice that self monitoring may prove useful to people with diabetes in their self management of the condition.

The Diabetes UK position statement on this subject is available on our website, www.diabetes.org.uk/position-smbg

Thank you for taking the time to read this letter. We hope it will encourage you to reassess your policy for home blood glucose test strips.

Yours faithfully

Diabetes UK Advocacy Service



Diabetes UK's Position Statement

Self-monitoring of blood glucose

People with Type 1 and Type 2 diabetes should have access to self-monitoring of blood glucose (SMBG) based on individual clinical need, type of diabetes, personal circumstances and informed consent - not on ability to pay. Ninety five per cent of diabetes care is self-care. As such, self-monitoring supported by education, is essential to inform the day-to-day lifestyle and treatment choices of individuals, as part of an integrated management strategy. Decisions about the type and frequency of self-monitoring should be made on a case-by-case basis and not on blanket decisions and removal of strips from prescriptions.

Diabetes is a life-long condition, and can have a profound impact on lifestyle, relationships, work, income, health, wellbeing and life expectancy. Clinical trials have demonstrated the value of tight glycaemic control to reduce the risk of costly and life threatening complications¹⁻⁷. Prolonged raised blood glucose levels are extremely detrimental to health, as it is associated with increased risk of heart disease, strokes, blindness, amputations and kidney disease⁸⁻¹⁰.

National guidelines and frameworks set the standards of care that people with diabetes should expect and prioritise information, education, training and support to enable people to manage their diabetes themselves¹¹⁻¹⁸. SMBG, by blood and/or urine testing, combined with education, provides information for people with Type 1 and Type 2 diabetes to make day-to-day decisions about food, physical activity and treatment to maintain optimum control of blood glucose.

The debate

It is generally recognised that routine SMBG is beneficial, when supported with education, for all people with Type 1 diabetes and those with Type 2 diabetes using insulin^{12, 17-20}. The debate largely focuses on the clinical and cost effectiveness of SMBG for people with non-insulin treated diabetes²¹⁻²³.

The Guideline Development Group (GDG) for the NICE Clinical Guidelines for Type 2 diabetes¹² felt that some studies added 'considerable confidence to the view that SMBG was an integral part of effective patient education packages and enabled the effective use of many other therapies and lifestyle interventions.' The current recommendations for SMBG included in the NICE Type 2 diabetes guideline are:

- Offer self-monitoring of plasma glucose to a person newly diagnosed with Type 2 diabetes only as an integral part of his or her self-management education. Discuss its purpose and agree how it should be interpreted and acted upon.
- Self-monitoring of plasma glucose should be available:
 - to those on insulin treatment
 - to those on oral glucose lowering medications to provide information on hypoglycaemia
 - to assess changes in glucose control resulting from medications and lifestyle changes
 - to monitor changes during intercurrent illness
 - to ensure safety during activities, including driving.
- Assess at least annually and in a structured way:
 - self-monitoring skills
 - the quality and appropriate frequency of testing
 - the use made of the results obtained
 - the impact on quality of life
 - the continued benefit
 - the equipment used.



- If self-monitoring is appropriate but blood glucose monitoring is unacceptable to the individual, discuss the use of urine glucose monitoring.

The open nature of these recommendations must not be used as an opportunity to impose blanket restrictions on access to blood glucose testing strips for some people with Type 2 diabetes. The GDG stated clearly that: 'The frequency of monitoring that is useful to someone with diabetes is highly individual and it is inappropriate to put an artificial restriction on this' ¹².

Current evidence is either lacking or contradictory. It can be argued that this is due to the limitations of the trials undertaken to date and the lack of focus on patient preferences. Sound evidence is needed to review all the factors contributing to optimum blood glucose management and its relationship to and with self-monitoring over time. This needs to include effects of education, actions taken by those self-monitoring, motivation, behaviour change, and patient related outcomes such as quality of life, wellbeing and satisfaction ²⁴. The current lack of evidence does not mean that SMBG is not effective for those not treated by insulin, it just means that there is no evidence. Research commissioned by Diabetes UK, and others, is in progress.

Costs and benefits

In 2001 the UK spent approximately £90 million on self-blood glucose monitoring ²⁵. It has been cited that more is spent on testing strips than on oral glycaemic agents. The implication being that this is not a good use of resources. This does not consider that for some people with diabetes, being able to monitor blood glucose levels may be as beneficial to them as taking the medication. In order not to waste resources it is important that people with diabetes are able to utilise self-monitoring effectively through diabetes education. Without the education to know when and how to test, and what to do with the results, there is little point in self-monitoring. It is short-sighted to look to reducing costs through restrictive policies that prevent people from having the information they need to self-care. This is likely to result in increased prevalence of complications, costs to society and individuals themselves.

Considerable cost savings and improvements in quality of life are to be made from supporting people with diabetes to self-care, in line with health policy, including improved health and wellbeing, prevention of unnecessary hospital admissions, and reduced frequency of support from the NHS ²⁶. People with diabetes do generally take on board the issues of cost and should use blood glucose testing responsibly and appropriately. Evidence has shown that SMBG is beneficial to, and valued by, people with diabetes to:

- enable better management of short-term and longer-term metabolic control ^{12, 22, 27-33} assisting in the prevention of short-term and long-term complications ³⁴
- monitor effectiveness of medication, eating and physical activity on blood glucose levels ^{33-36, 41}
- help to maintain or improve motivation for managing diabetes ^{36, 41}
- provide reassurance and reducing anxiety and fear of hypoglycaemia ^{28, 35}
- improve feelings of confidence and control over their own diabetes ^{28, 35}.

Local restrictions

An increasing number of people with diabetes are reporting restrictions or denial of blood glucose testing equipment causing distress and anger among those who rely on these tools to self-manage their diabetes ³⁷. Twenty seven per cent of PCTs in England ³⁸ report the existence of a policy restricting the provision of blood glucose test strips for people with diabetes.



Actions

- Decisions about blood glucose monitoring should be made on a case-by-case basis and not by blanket removal of strips from prescriptions or local restrictive policies. Local guidelines should be in place to encourage healthcare professionals to work in partnership with individuals with diabetes to inform them of the role that SMBG plays in self-management.
- Increased awareness is needed of the importance of people with diabetes being able to access appropriate tools and support to manage their own diabetes.
- Diabetes care teams should discuss the advantages and disadvantages of monitoring either by blood or urine, at diagnosis to enable people with diabetes to make informed choices. Those choosing to monitor their blood glucose should do so as part of an integrated package of care as defined in national guidelines.
- Training and education should be provided about testing methods, how to interpret results and how to use results to adapt diet, lifestyle and medication to achieve optimum control³⁹⁻⁴⁰. Methods and frequency of testing should be jointly agreed between the person with diabetes and healthcare professional through care planning. Any changes or reviews must only be made through discussion with, and agreement of, the person with diabetes.

This position should be interpreted as the basis upon which discussions are initiated about whether a person with diabetes wishes to or should monitor their blood glucose levels. The decision should be jointly agreed between the person with diabetes and their own healthcare team.

For further information see Diabetes UK Care Recommendation - 'Self Monitoring of Blood Glucose' reviewed January 2009. www.diabetes.org.uk/carerec-smbg

Position Statement updated for accuracy regarding the section on the NICE Clinical Guidelines for Type 2 diabetes (CG66) December 2009.



Some useful sources of support and information

National Institute for Health and Clinical Excellence (NICE)

The Guidelines for Type 2 diabetes 2008 are available at: www.nice.org.uk/CG66

Diabetes UK Advocacy Service

The Advocacy Service provides basic advocacy for people with diabetes to help them express their views and wishes and access information and services.

Telephone 020 7424 1840

Email advocacy@diabetes.org.uk

www.diabetes.org.uk/How_we_help/Advocacy

Diabetes UK Careline

The Careline provides support and information to people with diabetes as well as friends, family and carers. Careline@diabetes.org.uk or call 0845 120 2960 (please check the costs of calls to 0845 numbers with your phone provider). Or call 020 7424 1000 and ask to be transferred to Careline.

Patient Advice and Liaison Service (PALS) (England only)

The Patient Advice and Liaison Service help resolve concerns or problems when you are using the NHS in England. They provide information about the NHS complaints procedure and how to get independent help if you decide you may want to make a complaint. You can find your local PALS office telephone number in the phonebook, or at your nearest hospital/GP surgery:

www.pals.nhs.uk

Independent Complaints Advocacy Service (ICAS) (England only)

The Independent Complaints Advocacy Service supports patients and their carers wishing to pursue a complaint about their NHS treatment or care. ICAS services are provided by different organisations in different parts of England. All ICAS services are free.

In the North East, North West, Yorkshire and Humberside and the East Midlands, ICAS services are provided by the Carers Federation.

www.carersfederation.co.uk

In London, West Midlands and the East of England, ICAS services are provided by POHWER.

www.pohwer.org.uk

In the South East and South West, ICAS services are provided by SEAP.

www.seap.org.uk

Citizens Advice Bureau (CAB)

In Scotland the Citizens Advice Bureau is tasked with providing help for people making complaints about healthcare. In other parts of the UK the CAB may be able to help with this as part of its general advice service. The CAB offers free, confidential, impartial and independent advice. Advisers can help fill out forms, write letters and negotiate with third parties. Advice is available face-to-face and by telephone and some also provide email advice. The number of your local CAB will be in the phone book or you can also find your local CAB on their website. www.citizensadvice.org.uk

www.adviceguide.org.uk to find online help from citizens advice

Telephone 020 7833 2181 to find your local CAB office.

Community Health Council (CHC) Wales

The Community Health Council can give free impartial advice and help with making a complaint about healthcare in Wales.



www.patienthelp.wales.nhs.uk

Telephone 02920 235 558

Patient and Client Council (PCC) (Northern Ireland only)

The Patient and Client Council provide free impartial advice and help to people making a complaint about healthcare in Northern Ireland.

www.patientclientcouncil.hscni.net

Telephone 0800 917 0222

Parliamentary and Health Service Ombudsman (PHSO) (England Only)

The Ombudsman investigates complaints about the National Health Service (NHS) in England. The Health Service Ombudsman covers NHS hospitals, trusts and health authorities, GPs, dentists, opticians, pharmacists and other providers (including private health care) where the service is paid for by the NHS.

www.ombudsman.org.uk

Telephone 0345 015 4033 (complaints helpline)

Scottish Public Services Ombudsman (SPSO)

The Ombudsman is the final stage for complaints about organisations providing public services in Scotland.

www.spsso.org.uk

Telephone 0800 377 7330 (advice line)

Public Service Ombudsman for Wales

The Ombudsman looks into complaints about public service providers in Wales including the NHS.

www.ombudsman-wales.org.uk

Telephone 0845 601 0987 (complaints advice)

Northern Ireland Ombudsman

The Ombudsman considers complaints against the NHS in Northern Ireland.

www.ni-ombudsman.org.uk

Telephone 0800 34 34 24 (free phone)

Patients Association

The Patients Association provides independent information and advice on a range of healthcare issues. They campaign on behalf of patients and are interested to hear about any aspect of the patient experience.

www.patients-association.org.uk

Telephone 0845 608 4455

Diabetes UK Publications orderline: 0800 585 088 or visit www.diabetes.org.uk/Shop

Diabetes UK website: www.diabetes.org.uk

Please note the inclusion of named agencies does not constitute a recommendation or endorsement by Diabetes UK. Whilst every effort is made to ensure accuracy, Diabetes UK cannot be held responsible for errors or omissions.

This information should not be considered a complete guide to the law, which also changes from time to time. Legal advice should always be taken if in doubt. Diabetes UK is unable to give legal advice.



Advocacy pack feedback form

Could you please take the time to fill out this evaluation form and return it to Diabetes UK, Freepost LON 12857. Or you can save a copy on your computer and email it to us at advocacy@diabetes.org.uk

Your answers will help us to find out how useful the Advocacy Packs are and how we can improve them.

1. How did you use this pack?

- Personally, to help yourself
- Professionally, to help a client
- 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?

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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
- Employer Diabetes UK Careline
- Website *Balance* magazine
- Other

Please specify:

.....

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

.....

.....

Thank you for taking the time to complete this form.