

DIABETES EDUCATION ADVOCACY PACK

Please note that this pack is for adults with diabetes and does not cover education for children and young people with diabetes. Contact the Diabetes UK Advocacy Service for information about the rights of children with diabetes. Refer to the contact details at the back of this pack.

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1 GETTING A PLACE ON A DIABETES EDUCATION COURSE

Some people have difficulty securing a place on a diabetes education course. This pack sets out your rights and explains what you can do if you experience difficulties.

What are diabetes education courses?

Diabetes education courses are group sessions led by healthcare professionals or trained peer educators which aim to help you take control of your diabetes and live a full and healthy life. There are specific courses available for people living with Type 1 or Type 2 diabetes. Course content will vary from course to course, but all courses should suit your needs and be delivered by trained educators. You should be given the opportunity to improve your diabetes management skills, ask questions and meet other people living with diabetes.

The most commonly available courses are:

Course	Duration	Details
DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed), for adults with Type 2 diabetes www.desmond-project.org.uk	Six hours of education, usually in one day or half day formats	Helps participants understand their diabetes, including risk factors and complications, make food choices and take control. Available in Punjabi, Gujarati, Urdu or Bengali in some areas.
X-PERT Diabetes Programme , for adults with Type 2 diabetes www.xperthealth.org.uk	Two and a half hour sessions delivered over six weeks, plus annual follow up session	Participants explore how diabetes affects their body and how lifestyle changes can improve their diabetes control.
DAFNE (Dose Adjustment For Normal Eating), for adults with Type 1 diabetes www.dafne.uk.com	Five day training course, plus follow up session at eight weeks	Gives people the skills necessary to estimate the amount of carbohydrate in each meal and inject the right dose of insulin, so that they can fit diabetes into their own lifestyle.

There are also locally designed courses in some areas. Your healthcare professional team should be able to tell you what is available in your area.

When should I be offered the opportunity to attend a diabetes education course?

National guidelines state that everyone with Type 1 or Type 2 diabetes should have the opportunity to attend an appropriate diabetes education course.

People with Type 1 diabetes should be offered a place on a course between six and 12 months after being diagnosed. If you have had Type 1 diabetes for over 12 months and have not yet attended a course, you should be offered a place at any point that is suitable for you. Your self-care needs should also be reviewed annually by your diabetes team.

People with Type 2 diabetes should be offered a place on a course shortly after diagnosis. If you have Type 2 diabetes, your need for this type of education should be reviewed each year as part of your ongoing diabetes care, and you should be offered the opportunity to attend more than once if appropriate.

What do I need to do to attend a course?

This depends on the course and your local area. For some courses, you can self-refer and for others the referral needs to come from a healthcare professional (such as your GP, practice nurse or diabetes consultant). Ask your healthcare professional for a referral. Alternatively contact the local course provider or your local decision makers (see box below) to find out whether you can self-refer.

Health decision makers vary depending on where in the UK you live. **Clinical Commissioning Groups** are the bodies responsible for making health decisions in England. In Scotland, **NHS Boards** have this responsibility and in Wales, **Local Health Boards** do. In Northern Ireland, the responsible body is **Health and Social Care Trusts**.

What if my healthcare professional says there are no courses in my area?

You should have access to a diabetes education course. If there are none in your area, you may want to make a healthcare complaint. See our *Making A Complaint About Healthcare* Advocacy Pack for more information on how to do this. You can also write to your local decision maker directly, there is a template letter on our website at www.diabetes.org.uk/taking-control

If you want to campaign to improve the availability of education courses for people in your area, becoming a Diabetes Voice could help. **Diabetes Voices** is our network for people who want to raise their voice to improve the lives of people living with diabetes across the UK. Our Diabetes Voices work with us to campaign and influence for improvements in diabetes services and care. For more information and to get involved, see the Diabetes Voices contact information at the end of this pack.

What if my healthcare professional doesn't think I need to attend a course?

In England and Wales, national clinical guidelines state that education courses are an integral part of diabetes care and therefore should be offered to **all** people with diabetes¹. If you were not offered a course around the time of diagnosis, you should be

allowed to attend at any time that is appropriate for you. The guidelines also state education should be accompanied by an annual review, so if you think you would benefit from attending again at any stage you should discuss this with your healthcare professional.

In Scotland, national clinical guidelines state that education courses should be offered to all adults with Type 2 diabetes and adults with Type 1 diabetes who are experiencing problems with hypoglycaemia or failing to achieve glycaemic targets².

In Northern Ireland, the Executive's Programme for Government (2011–2015) commits to enrol everyone who has a long term condition in a self-management programme (if they want to attend one)³.

These guidelines (and the commitment in Northern Ireland) are based on evidence that shows that diabetes education improves people's health and reduces their risk of serious complications.

If your healthcare professional doesn't think you need to attend a course, you can explain to them why you feel you need to go on one, how it would help and also that these courses are recommended as outlined above.

Can I take somebody with me?

The national guidelines for England and Wales state that education should be offered to the carers of people with diabetes. Courses will also often allow you to bring a friend, family member or partner along with you, so do ask your course provider or healthcare professional if this is possible.

What if I am unable or unwilling to attend a course?

National guidelines for England and Wales state that people who are unable or unwilling to attend group education courses should be offered an alternative of an equal standard. The guidelines do not say what form this should take, but it is likely to involve one-to-one coaching. You can also refer to Section 3 of this pack on page 6 (other learning and support options).

If you would like to find out more about the Diabetes UK Taking Control campaign go to www.diabetes.org.uk/taking-control

2 TAKING TIME OFF WORK TO ATTEND A DIABETES EDUCATION COURSE

Should I be allowed time off work to attend a course?

Your right to time off work can come from your statutory rights, which is when the law gives you the right to time off in certain circumstances. Your right to time off work can also come from your contract of employment. The right to time off work does not always entitle you to paid leave.

Your contract of employment can sometimes give you extra rights, over and above what the law says. It is therefore important that you check your contract. A contract of employment does not simply refer to your written contract but also anything that has been agreed verbally or has been established through custom and practice.

Under the Equality Act 2010, if you have a disability your employer has a duty to make reasonable adjustments in order to prevent you, as a disabled employee, from being placed at a substantial disadvantage. A failure by an employer to do so constitutes unlawful disability discrimination under the Act.

What is classed as a disability under the Equality Act 2010?

The Equality Act 2010 defines a disability as:

“A person has a disability if they have a physical or mental impairment and this impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.”

The term substantial does not mean that a person is unable to carry out the activity at all. If the person can carry out the activity more slowly than usual or only for short periods of time then this would be considered to be a substantial effect as the effect must be more than minor or trivial.

For an impairment to be considered long-term the effect of the impairment must have lasted, or be likely to last, a minimum of 12 months.

If a person is taking medication to treat their condition then the effect of not taking their medication would be taken into account.

The definition of disability under the Act is not reliant on a specific diagnosis. What is important is the effect of the health condition on the individual.

Example

Take the example of a person with diabetes being treated with medication or diet. Whether or not their impairment has a substantial adverse effect should be decided by looking at what the effects of the condition would be if the person was not taking their medication, or following the prescribed diet⁴.

What is a reasonable adjustment?

The duty to make reasonable adjustments falls into three categories:

- Where the employer applies a provision, criterion or practice which puts a disabled person at a substantial disadvantage compared with people who are not disabled. The employer must then take reasonable steps to avoid the disadvantage.
- Where a physical feature puts a disabled person at a substantial disadvantage compared with people who are not disabled. The employer must then take reasonable steps to avoid the disadvantage.
- Where a disabled person would, but for the provision of an auxiliary aid (see box below), be put at a substantial disadvantage compared with a person who is not disabled. The employer must then take reasonable steps to provide the auxiliary aid.

An auxiliary aid and/or service is defined as a particular piece of equipment, an aid or assistance that will help you to carry out your work. This could include providing special equipment or modifying existing equipment – for example, providing adapted desks, chairs or keyboards but it could also include providing extra support, ie extra training.

What is a substantial disadvantage?

A substantial disadvantage means a disadvantage that is more than minor or trivial.

Is the adjustment requested reasonable?

The law does not specify exactly what would be considered to be a reasonable adjustment as the type of adjustment a person may need is dependent on their individual needs.

Examples of reasonable adjustments can include, but are not limited to, the following:

- Changing working times.
- Frequency of breaks.
- Allowing time off to attend medical appointments.
- Alterations to work premises/equipment.
- Allowing time off work to attend education courses.

Factors which are particularly relevant when considering whether an adjustment is reasonable are:

- The extent to which the adjustment would prevent the disadvantage.
- How practical it is for the employer to make the adjustment.
- The employer's financial and other resources.
- Whether there is any available financial or other assistance to make the adjustment.
- The cost of the adjustment.
- The amount of disruption the adjustment may cause.
- The cost of not making the adjustment.

What is reasonable will vary from one situation to another and will depend on the individual circumstances of both the disabled employee and the employer.

Whether or not an employer has failed to comply with their duty to make a reasonable adjustment under the Act is a decision that ultimately lies with an Employment Tribunal who would apply an objective test to reach their decision. The Employment Tribunal would reach its own decision as to what steps were reasonable and objectively justified.

Your employer is under no duty to make a reasonable adjustment if they are not aware of your disability and cannot be reasonably expected to know that you have a disability.

How should I request time off to attend a course?

If you have not already done so, the first step is to have a conversation with your employer about your diabetes and that you consider yourself to come under the Equality Act's disability definition. You can then explain that a diabetes education course is an integral part of your diabetes care. You therefore consider time off to attend a course to be a reasonable adjustment under the Equality Act.

It may also be helpful to explain the benefits of attending to your employer. In particular it may be helpful to explain that better diabetes management could mean less time off work due to sickness related to your diabetes. By achieving better diabetes management this could also reduce your risk of complications, which may otherwise have meant you needed to take time off work.

It may also be helpful to ask your healthcare professional to provide a letter stating that an education course is an integral part of your diabetes care and outlining the benefits of attending.

Should your employer refuse your request there are options available to you if you are unhappy with their decision. Please refer to our *Employment and Diabetes Advocacy Pack* for details of these options.

3 OTHER LEARNING AND SUPPORT OPTIONS

Diabetes UK recommends that you attend a face-to-face diabetes education course as soon as you're ready. However, there are also many other learning and support options available to you.

- **Type 2 Diabetes and Me** is an interactive online course to help people with Type 2 diabetes understand and manage their condition successfully. It was developed by Diabetes UK, in partnership with Bupa. www.diabetes.org.uk/Guide-to-diabetes/Managing-your-diabetes/Education/Type-2-diabetes-and-me
- **Living with Diabetes Days** are free education days, hosted by Diabetes UK and held across the UK, for people newly diagnosed with Type 2 diabetes and those who have little knowledge of how to manage their condition. It's a perfect opportunity to find out what Type 2 diabetes is, learn about the care you should get, and take part in workshops on things like diet, exercise, medication, avoiding complications, travel and driving. www.diabetes.org.uk/How_we_help/Living-with-Diabetes-Days
- **Diabetes UK Care Events** are run across the UK and are aimed at children, young adults and families living with diabetes. They provide people living with diabetes opportunities to share and learn from each other in a relaxed and safe environment. www.diabetes.org.uk/How_we_help/Care-events

Diabetes UK support

1 Call our dedicated diabetes Careline.

The confidential helpline is staffed by trained counsellors who have extensive knowledge of diabetes. They can provide information about the condition, take the time to talk things through and explore emotional, social, psychological or practical difficulties. They are available between 9am–7pm, Monday – Friday. Call 0345 123 2399* and ask to speak to Careline or email careline@diabetes.org.uk.

- 2 Talk to someone with diabetes.** If you would like to talk to someone who knows first-hand what it's like to live with diabetes, our support volunteers are here to help. You can ask questions, get practical advice, or just have a heart-to-heart chat with someone who understands. You can reach them by phone between 6pm–9pm, Sunday to Friday on

0843 353 8600, or by emailing talktosomeone@diabetes.org.uk. Go to www.diabetes.org.uk/How_we_help/Peer-Support for more information and to view our volunteer profiles.

- 3 Join our online communities.** Go to www.diabetessupport.co.uk, or find us on Facebook or Twitter.
- 4 Sign up to a Diabetes UK local support group** to meet and share experiences with others. For more information, call 0345 123 2399* or go to www.diabetes.org.uk/How_we_help/Local_support_groups
- 5 Order free resources from our online shop** to help you manage your diabetes and live a healthy life. Go to shop.diabetes.org.uk, or call 0345 123 2399* and ask for a catalogue.

The organisations below may be useful for further support in accessing diabetes education:

Diabetes UK Advocacy Service

The Advocacy Service supports people to take action by providing information on rights and discussing possible action that can be taken.

Web: www.diabetes.org.uk/How_we_help/Advocacy

Email: advocacy@diabetes.org.uk

Telephone: 0345 123 2399*

Diabetes UK Diabetes Voices

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

Web: www.diabetes.org.uk/Get_involved/Campaigning/Diabetes-Voices

Email: diabetesvoices@diabetes.org.uk

Telephone: 0345 123 2399*

For help making a complaint

See our ***Making A Complaint About Healthcare Advocacy Pack***.

Web: www.diabetes.org.uk/How_we_help/Advocacy/Advocacy-packs/Making-a-complaint-about-healthcare

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

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

PALS can help resolve concerns or problems when you are using the NHS in England. They can provide information about the NHS complaints procedure and how to get independent help if you decide you want to make a complaint.

More information on PALS can be found on the NHS Choices website, which also has a search tool to find the nearest PALS in your area:

Web: www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68

You can also ask your GP surgery or hospital for details of your nearest PALS.

NHS Complaints Advocacy (England only)

The NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about an NHS service. Their website has information on how to make a complaint and the support they can provide. They also have a self-help pack which you can request or download.

Web: nhscomplaintsadvocacy.org

Email: nhscomplaints@voiceability.org

Telephone: 0300 330 5454 (helpline)

Citizens Advice Bureau (CAB)

In Scotland the CAB is tasked with providing help for people making complaints about healthcare through its Patient Advice and Support Service (PASS) (Scotland only). Contact your local CAB for more information.

Web: www.cas.org.uk/about-us/partnerships-services/cab-service-partners/patient-advice-and-support-service or contact your local CAB.

In other parts of the UK the CAB may be able to help with this as part of its general advice service.

The number of your local CAB will be in the phone book or you can also find your local CAB on their website.

Web: www.citizensadvice.org.uk
(England and Wales)

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

Telephone: England: 03444 111 444
Wales: 03444 77 20 20

Community Health Council (CHC) (Wales only)

Your local CHC can give you free impartial advice and help with making a complaint about healthcare in Wales. To find details of your local CHC contact the Board of Community Health Councils in Wales.

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

Email: enquiries@waleschc.org.uk

Telephone: 02920 235 558

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

The PCC offers free impartial advice and help to people making a complaint about healthcare in Northern Ireland.

Web: www.patientclientcouncil.hscni.net

Email: info.pcc@hscni.net

Telephone: 0800 917 0222

Parliamentary and Health Service Ombudsman (PHSO)

The PHSO is the health ombudsman for England.

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

Web: www.ombudsman.org.uk

Email: phso.enquiries@ombudsman.org.uk

Telephone: 0345 015 4033 (Complaints helpline)

Scottish Public Services Ombudsman (SPSO)

The SPSO is the health ombudsman for 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

Email: Using online complaint form at www.spsso.org.uk/complain/form/start

Telephone: 0800 377 7330 (Advice line)

Public Services Ombudsman for Wales (PSOfW)

The PSOfW is the health ombudsman for 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 or using online contact form at www.ombudsman-wales.org.uk/Contact%20us.aspx

Telephone: 0300 790 0203

Northern Ireland Ombudsman

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

Web: www.ni-ombudsman.org.uk

Email: ombudsman@ni-ombudsman.org.uk or using online form at www.ni-ombudsman.org.uk/Contact-Us.aspx

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

Care Quality Commission (CQC)

The CQC works to make sure that hospitals, care homes, dental and GP surgeries, and all other care services in England provide people with safe, effective, compassionate and high-quality care, and encourage them to make improvements. They inspect services and publish the results on their website to help people make better decisions about the care they receive.

Web: www.cqc.org.uk

Email: enquiries@cqc.org.uk or using their online form www.cqc.org.uk/home/contact-us/contact-us-using-our-online-form

Telephone: 03000 61 61 61

The Patients Association

The Patients Association advocates for better access to accurate and independent information for patients and the public; 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

Telephone: 0845 608 4455 or 020 8423 9111

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.

References

- 1 NICE (2015). *NG17: Type 1 diabetes in adults: diagnosis and management*; NICE (2009). *CG87: Type 2 diabetes: The management of Type 2 diabetes*
- 2 SIGN (2010). 116: *Management of diabetes. A national clinical guideline*
- 3 Northern Ireland Executive (2011). *Programme for Government 2011–2015*
- 4 Office for Disability Issues, Equality Act 2010 Guidance. Guidance on matters to be taken into account in determining questions relating to the definition of disability

About Diabetes UK

Diabetes UK is the charity for people with diabetes, their family, friends and carers.

Our mission is to improve the lives of people with the condition and work towards a future without diabetes.

Diabetes UK is one of the largest patient organisations in Europe. We stand up for the interests of people with diabetes by campaigning for better standards of care. We are the largest funder in the UK of research into better treatments for diabetes and the search for a cure.

We provide support and information to help people manage their diabetes.

*Calls may be recorded for quality and training purposes.

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