



Insulin Dependent Diabetes Trust

Your Diabetes - Know Your Rights

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At the time of preparing this leaflet, we still do not know exactly how the NHS will be run, who will provide our care and treatment or how we as patients, will be able to ensure that we receive the high quality care that we have been promised, and to which we are entitled.

What we do know is that there are going to be changes. We also know that there are going to be cuts in expenditure, some of which are already being made. This could affect the supply of drugs you take, the numbers of blood glucose strips you are prescribed or a reduction in the number of referrals to specialists by GPs.

Knowing your rights

The NHS Constitution

“The NHS Constitution was created to protect the NHS and make sure that it will always do the things it was set up to do in 1948 – to provide high quality healthcare that’s free and for everyone. No government will be able to change the Constitution, without the full involvement of staff, patients and the public” [NHS website]

What is the Constitution?

The Constitution brings together in one place, the details of what staff, patients and the public can expect from the NHS. It sets out your rights as an NHS patient and also your responsibilities. The rights cover how patients access health services, the quality of care you should receive, information about the treatments and programmes available to you, confidentiality and your right to complain if things go wrong. The NHS also makes certain pledges to you, which it is committed to achieving. These go above and beyond your legal rights and are a commitment to provide high-quality services.

The whole of the NHS Constitution is available online:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613

Of specific interest to us in respect to being denied access to treatments has to be about our rights to choice.

These are your rights:

- **You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.** Your doctor should listen to you and respond to your concerns and preferences about your healthcare. That way, you can find out what is the best treatment for you. NHS staff will give you the information that you need to support these discussions and decisions.
- **You have the right to accept or refuse treatment that is offered to you,** and not to be given any physical examination or

treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests.

- **You should always be treated with dignity and respect.**

Tips

Choice of treatments

Your doctor or other healthcare professional should discuss with you your choices of treatment. The more you know about your condition and treatment options, the easier it is to make your views known. It is important to explain to your doctor your needs and the reasons for making your choices.

Scientific evidence

It maybe that the doctor will say there is strong scientific evidence to suggest that one treatment is better than others but there are still decisions and choices to be made. You can always ask the doctor for the scientific evidence and take it away to read before you make your decision, eg in Type 1 diabetes changing insulin type or in Type 2 diabetes making lifestyle changes before further medication.

In other cases, it may be less clear which treatments are best. For instance, with diabetes the newer insulins or drugs for Type 2 diabetes often do not show superiority over the old ones, so in these cases it is particularly important to ensure that you understand the options and make your views known. Another example of choice is the treatment of depression – you may prefer to see a counsellor rather than take antidepressants.

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NICE Quality Standards for adults with diabetes

A key element of ensuring that you receive good care and get the

most out of an appointment is to know your rights. You should know what standards of care you are entitled to, what to do if you feel you are not getting them and the support on offer to you if this is the case. The National Institute for Health and Clinical Excellence (NICE) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. It has issued a set of quality standards for adults with Type 1 and Type 2 diabetes. These quality standards lay down what level of care you should receive in relation to the management of your diabetes.

The aim is that the Quality Standards will help the NHS to deliver the best outcomes from treatments for patients by:

- Helping patients to understand what service they can expect from their health and social care providers, eg GPs, consultants, nurses
- Helping health and social care providers to make decisions about your care based on the latest evidence and best practice.
- Enabling NHS Trusts to examine the standards of care they provide against the Quality Standards they should provide and to enable commissioners of services to be sure they are providing high quality and cost effective services.

Quality Standards for Diabetes

These are basically the same as the standards laid down in the National Service Framework for Diabetes so here is what you should receive.

1. A structured education programme, annual review and ongoing education.
2. Personalised advice on nutrition and physical activity from a suitably trained healthcare provider.
3. Participation in annual care planning to agree goals and an action plan.
4. Agreement with your health professional of your target HbA1c and an ongoing review to minimise hypoglycaemia.
5. Agreement with your health professional to start, review and stop medications to lower blood glucose, blood pressure and blood lipids [cholesterol].
6. Trained health professionals to start and manage treatment with

insulin as part of a structured education programme which includes learning dose adjustment.

7. Women of childbearing age should be regularly informed about the importance of preconception blood glucose levels and any risks, including medication, to the unborn child. If a pregnancy is planned, preconception care should be offered and if not, they should be offered contraceptive advice.
8. An annual assessment for complications and their management.
9. An assessment for psychological problems which, if present, should be appropriately managed.
10. People with, or at risk of, foot ulceration should receive regular reviews by a foot protection team. Those with a foot problem requiring urgent attention should be referred to a foot care team within 24 hours.
11. If admitted to hospital your care should be managed by appropriately trained staff. You should have access to a specialist diabetes team and given the choice of self-monitoring and managing your own insulin.
12. If you are admitted to hospital with ketoacidosis, you should receive educational and psychological support before being discharged and followed up by a specialist diabetes team.
13. If you have experienced hypoglycaemia which required medical attention, then you should be referred to a specialist diabetes team.

The full details can be found at:

<http://www.nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp>

Remember this is the care that you should receive and it is part of the government's promise to make sure that the standards of care are high quality.

If you are not receiving this standard of care, then you need to say so. There can be subtle ways of doing this, such as asking when you are going to receive the education programme that you should have or the slightly less subtle ways, such as writing to your GP practice manager or your local Primary Care Trust.

Only half of patients have enough information to manage their condition

A structured education programme, annual review and ongoing education – point 1 in the Quality Standards

A study of 4500 people with three chronic conditions, asthma, Type 2 diabetes and heart disease was carried out in eight European countries and the US [commissioned by the pharmaceutical company, Pfizer]. It showed that in the UK:

- Nearly half [48%] of people are concerned that they do not know enough about their conditions and its treatments to confidently manage them.
- About half [49%] of people felt that a lack of knowledge might be worsening their conditions.
- When patients do receive health information on how to manage their condition, only half [49%] made proactive changes in their behaviour, based on the information they received. However, nearly three quarters [74%] of those who did change their behaviour reported health benefits.
- People use a wide number of sources of information, pharmacists, books, TV and radio and the internet [10%] with 91% looking to doctors and nurses as the main source of information.

The survey demonstrated that people need more and better information but it also showed that having information does not necessarily produce a change in behaviour. So it is essential that along with better education programmes, patients with chronic conditions are provided with support and help to enable them to make behavioural changes.

Sources of information

With only half of patients feeling that they have sufficient information, there certainly is a great need for more and better information for patients. But the sources of such information must be reliable, accurate and uninfluenced by anything other than the patients' best interest. Pharmaceutical companies want the EU to allow them to supply information directly to patients. We must remember that pharmaceutical companies have a vested interest in the promotion of their drugs so they are not an independent source of information.

Having a care plan

Participation in annual care planning to agree goals and an action plan – point 3 in the Quality Standards.

103 GP practices ran a care programme which has shown that 11,000 lives could be saved every year with better care for people with diabetes. In just 10 months the programme demonstrated how simple changes can have dramatic effects. The study involved 24,000 patients, nurses and GPs in a more systematic approach to treatment.

This included:

- Creating and maintaining an accurate record of patients.
- Calling patients in for regular checks.
- Training them to become experts at managing their diabetes.
- Creating a network of care that included GPs, primary care trusts and hospitals.

The programme has shown what is possible by measuring the proportion of patients who achieved the correct levels of blood sugars, cholesterol and blood pressure and who were also screened for retinopathy.

If the results from this programme could be reproduced nationally it would mean:

- 35,100 fewer patients would have diabetic complications
- 28,500 fewer people with diabetes would suffer heart attacks or strokes
- 11,600 fewer deaths every year.

It is expected that the techniques developed in the trials will be spread to the rest of the NHS.

Equality Act 2010

On October 1st 2010 the new Equality Act 2010 came into force in

England, Scotland and Wales. The aim of the new Act is to simplify and draw together various parts of the previous legislation, including the Disability Discrimination Act.

The areas covered include employment, education and access to goods and services. In terms of employment, employers are obliged to make 'reasonable adjustments' to enable people with disabilities to work and prevent them from being disadvantaged.

Who does the Act cover?

A person is classed as having a disability if physical or mental impairment has a substantial, long-term effect on their abilities to carry out normal day to day activities. Whether a condition can be classed as disabling is decided on the effects on the person of not taking medication or not following a required diet.

So people with diabetes are covered by the Equality Act 2010 as they have to take their medication at appropriate times and may have to eat at set times to control their blood sugars. For instance, people with diabetes may have to take their breaks at different times from other employees and employers making this possible would be seen as making a reasonable adjustment. These same principles would apply to children with diabetes in education.

Further details of the Equality Act 2010 can be found at www.equalityhumanrights.com for England, Scotland and Wales and www.nihrc.org for Northern Ireland.



At your Consultation

The 9 key tests to be carried out annually

NICE recommends that people with diabetes should receive 9 key tests that you should receive at least once a year, at your hospital or GP appointment for your diabetes. They are:

- Weight measurement
- Blood pressure
- Smoking status,
- HbA1c
- Urinary albumin
- Serum creatinine
- Cholesterol
- Eyes
- Feet

However, many people are not receiving all 9 key tests, as shown by the National Audit for adults with diabetes and the National Paediatric Audit for Children and young people with diabetes.

The National Audit issued in 2010 for the years 2008/9 showed that thousands of adults with diabetes are still missing some of these 9 key tests.

- Only a third of people with Type 1 diabetes received all 9 tests and just over 50% of those with Type 2 diabetes received all 9 tests.
- Measuring urine albumin creatine ratio, which detects early kidney disease was the least likely to be carried out. Blood pressure measurement was the most frequently recorded test - 88.8% for people with Type 1 and 96.5% for those with Type 2 diabetes.
- Social deprivation did not affect the likelihood of all the tests being carried out but age did have an effect, with younger people receiving tests less frequently. Of people aged 16 to 39, just over 20% with Type 1 and just over 35% with Type 2 diabetes received all the tests compared with just over 34% and just over 51% respectively in the 40–84 age group.
- 90% are in contact with their healthcare teams at least once a year but the audit showed that the high level of contact with healthcare teams is not always being converted into effective care. Half of people do not meet blood pressure treatment targets, a third have 'poor' blood glucose control, particularly younger people.

There have been improvements from 6 years ago when the audit was carried but NICE recommended targets are still not being met.

Worryingly younger people and those with Type 1 diabetes seem to be missing out more on the care they receive.

The National Paediatric Audit 2009/10 for England and Wales shows that 96% of children and young people with diabetes may not have received all 9 of the key test.

The audit looked at the records of 19,558 children and young people between the ages of 0 to 24 years. Of these, 18,451 were between the ages of 0 to 17 years. Not all 9 key tests are recommended for all age groups but the guidelines specify a starting age of 12 years.

- 94.3% were recorded as having Type 1 diabetes and 52% were male. 1% had Type 2 diabetes.
- 96% of children and young people may not have had all the 9 key tests carried out and this has fallen by 1% since the 2008/09 audit.
- 89.3% of children and young people had their HbA1c results recorded but in children and young people over 12 years, only 4.1% had all 9 key tests recorded.
- Only 14.5% of HbA1c results were within the NICE recommended target of less than 7.5% [59mmol/mol] and this is worse than previous years. The highest numbers who achieved the targets were children from 0 to 4 followed by the 5 to 11 age group. Over 30% of children and young people have high risk HbA1cs greater than 9.5% [82mmols/mol].
- 9.0% had 1 episode of DKA [diabetes ketoacidosis] in 2009/10. DKA was more common in girls than boys, more common in the teenage years and often recurrent.

There was a large variation in DKA recurrence rates and considerable variations in meeting HbA1c targets between treatment centres. The audit concludes that, even though everyone is using the same treatment tools, some approaches are systematically better than others and it is expected that if the more effective systems are more widely used, then overall improvements would be achieved.

Recommendation – see the back of this leaflet for a chart to complete at each of your visits. It lists the 9 tests that should be carried out at your annual review. At your review ask if all 9 tests have been carried out. If so, tick the box but if not, ask why not and if necessary, ask for the tests to be carried out.

Getting the most from your appointment with your doctor or healthcare professional

At some time or another people with diabetes come across a wide variety of health professionals. This may include GPs, Practice Nurses, Dietitians, Diabetes Specialist Nurses [DSNs], Podiatrists and a range of Hospital Consultants. Sadly, it is often the case that people come away from appointments feeling confused about their treatment or feeling that they have not got what they wanted from the visit. This can be because people feel nervous or for a variety of other reasons, such as 'I didn't want to bother the doctor', 'Once I was there, I forgot to ask' or 'He's always busy and I didn't want to take up his time.'

It is important that you get the most out of any appointment with any member of your diabetes healthcare team. Here are some tips on how to manage the actual appointment or consultation effectively.

Some tips for your appointment

- **Be prepared.** Make a list of what you want to get out of the consultation and write down the questions you want to ask. If you feel there are a lot of issues to discuss, ask to make a double appointment so that the surgery can keep to time and you don't feel rushed.
- **Be informed.** Do your research before you go so that you are aware about things like the various treatment options that may be available. Stay focused on the topic. Don't hand your doctor /

healthcare professional anything to read until after your discussion is over because he/she will start reading it and will no longer be focused on you and your questions.

- **Be honest with your healthcare professional.** If you are honest with them about your diabetes or related condition, then you will be able to be treated more effectively. They can't be expected to help if they haven't got the full picture.
- **Communication.** Make sure your healthcare professional knows why you have come and they fully understand the nature of the problem. Have mutual respect. Respect is a two way thing, you should respect your healthcare professional for their medical knowledge but they should also respect you for your experiences as a patient.
- **Make joint decisions.** Having mutual respect will allow you both to make decisions that you are both happy with.
- **Taking your partner or friend.** If you would feel more comfortable, take you partner or a friend with you and check that your health professional is happy with this.
- **Be practical.** Think ahead about your medication and make sure that you have enough supplies by marking on a calendar or diary when you need to order more. This is particularly important at holiday time.

can help you. Its role is to make sure your concerns reach the right people and to support you in resolving any problems you may have. It can help you to make a complaint and introduce you to agencies and support groups outside the NHS.

- You can also raise your concerns by getting in touch with regulatory bodies, such as the Care Quality Commission.

The Parliamentary and Health Service Ombudsman

If you have tried the NHS complaints procedure but are dissatisfied with the response, you can contact the Parliamentary and Health Service Ombudsman. The Ombudsman carries out independent investigations into complaints about government departments, their agencies and the NHS. The details are as follows:

Complaints Helpline: 0345 015 4033, open Monday to Friday 8.30 am to 5.30pm or e-mail phso.enquiries@ombudsman.org.uk or you can write to:

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

PALS – what it is and what it does

The Patient Advice and Liaison Service, known as PALS, was introduced to ensure that the NHS listens to patients, their relatives, carers and friends, and answers their questions or resolves their problems as quickly as possible.

The NHS employs over a million people and provides a broad range of services, so it is not surprising that sometimes in a hospital situation, you may feel confused or concerned about various issues. This can be particularly difficult if you are feeling vulnerable or anxious.

While the NHS expects its staff to listen and respond to patients, it doesn't always happen and sometimes you may wish to talk to someone who is employed to help you so that your questions and concerns are resolved as quickly as possible. This is what PALS is there to do. PALS offices are usually located within or near to hospitals

The right to complain

The NHS Complaints Procedure

The NHS has its own complaints procedure. You have the right to have any complaint you make about the NHS dealt with efficiently and have it investigated properly. Here's what to do if you wish to make a complaint against an NHS organisation eg your hospital or your GP.

- You should first contact them directly.
- If you are not sure where to start or how to get in touch with an NHS organisation, the Patient Advice and Liaison Service [PALS]

so that you have on the spot access to help.

What PALS does for you:

- ▶ Provide you with information about the NHS and help you with any health-related enquiry.
- ▶ Help to resolve concerns or problems when you are using the NHS.
- ▶ Provide information about the NHS complaints procedure and how to obtain independent help if you decide you want to make a complaint.
- ▶ Provide you with information and help to introduce you to agencies and support services outside the NHS.
- ▶ Tell you how you can get more involved in your own healthcare and the local NHS.

What PALS does for the NHS:

- ▶ Improve the NHS by listening to your concerns, suggestions and experiences and ensure that people who design and manage services are made aware of the issues you raise.
- ▶ Provide an early warning system for NHS Trusts and those that monitor them by identifying problems or gaps in services and reporting them.

If you want to know more about PALS and how to find your local PALS office, then visit the website: www.pals.nhs.uk

Reporting adverse drug reactions

Reporting side effects of drugs, also called adverse reactions, is an important part of improving the safety of drugs. Monitoring of these reports forms part of the post-marketing surveillance of drugs. Adverse drug reactions may not show up in the trials carried out for a drug to gain marketing approval but can show up once a drug has reached the market and is used on a wider population than just the pre-marketing trials. Adverse drug reactions can occur immediately after taking a drug [such as insulin] or after days, weeks, months or even years later.

In order to report an adverse reaction, you only have to suspect that the drug is causing the adverse effects, you don't have to prove it.

How to report adverse reactions in the UK

You can report any suspected adverse reactions you experience, here's how to do it.

- If you have access to the internet: go to www.yellowcard.gov.uk and CLICK on submit a Yellow Card report. On this site you can also check the adverse reactions reports already made.
- If you prefer to use a paper Yellow Card reporting form: telephone the MHRA on 0207 084 2000 or e-mail patientreporting@mhra.gsi.gov.uk and ask for a form to be sent through the post.

Restrictions on diabetes drugs

On April 12th 2011, the GP magazine, Pulse, published a list of drugs that GPs have been banned from prescribing due to their higher costs. Pulse used the Freedom of Information Act to conduct a survey of Primary Care Organisations and found that more than 50% of the 134 organisations questioned 73 had placed drugs on black lists or put restrictions on how these could be prescribed. Among those black-listed were the Type 2 drugs Byetta, Januvia, Victoza and Galvus. These newer drugs tend to be prescribed for people who have not responded well to the cheaper alternatives or who have had side effects to them. Naturally this raises fears that people will have to use cheaper alternatives that do not suit them as well, or they will be moved on to insulin earlier, which has more side effects, namely increased risk of hypoglycaemia.

Rationing of medicines – patients having to fight to gain access to medicines

Unless a treatment has been recommended by a NICE technology appraisal, Primary Care Trusts [PCTs] are allowed to decide not to fund a particular treatment. If a treatment is not routinely covered by a PCT and a GP or consultant wishes to prescribe such a treatment, then they can submit funding requests to the PCT.

Figures published in GP [28.04.11] show:

- Funding requests to PCTs rose by 17% from 2008/9 to 2010/11.

- Around half of requests are approved, but approval rates vary from less than 10% in some PCTs to more than 80% in others.
- During this period, 9,000 more requests were received but 1,000 fewer requests were approved.

[Source: Freedom of Information Act responses from 103 PCTs in England]

What about patients' rights?

This situation leads to conflicts between PCTs' freedom to make individual decisions and the NHS Constitution which defends patients' rights. There cannot be blanket bans on certain treatments because the NHS Constitution states that PCTs "must consider exceptional individual cases where funding should be provided."

The Audit Commission has estimated that the NHS in England could save more than £500 million a year if it cut the use of low clinical value treatments, such as unnecessary or cosmetic treatments. However, many PCTs go well beyond restricting treatments of low clinical value. They are also refusing to fund treatments or therapies that are approved by NICE. This includes pump therapy and diabetes education – a short-sighted policy which not only adversely affects the long-term health of people with diabetes but also increases costs in the long-term due to the earlier onset of complications.

Will GP Commissioning make this worse?

PCTs are in place until about 2013 when the system is expected to change and GP consortia are expected to be in charge of funding. It remains to be seen whether this will make the situation better or worse however, one thing is clear, if patients do not receive the treatment they need, then the complaint or argument will be directly with their GP and no longer the PCT. This is probably not a comfortable position for either the patient or the GP and is likely to make the doctor /patient relationship difficult.

How do we deal with this situation?

Perhaps now more than ever, we need to be aware of the NHS Constitution and our rights as patients.

Know Who Is Treating Your Diabetes

Competency Framework for Diabetes Nursing

As patients we may not be fully aware of the different nursing roles involved in diabetes or indeed, that there is a framework for levels of competency for the various nursing roles. The third edition of 'An Integrated Career and Competency Framework for Diabetes Nursing, has been produced by Training Research and Education for Nurses in diabetes [TREND UK]. It can be found at www.trend.uk.org The aim of the Framework is to support commissioning of appropriate levels of nurses to deliver diabetes services and to provide a clear definition of the nursing roles and their expected competencies. The new edition incorporates five new areas – screening and prevention of Type 2 diabetes, mental health, end of life care, prisons and young offenders units and nursing and residential homes.

Diabetes nursing is essential

This statement is clearly laid down and one that none of us, as patients would disagree with. Lest we forget, it also tells us that the role of diabetes nursing is:

- To make a difference to the lives of people with diabetes.
- To promote and maintain the health of people with diabetes.
- To promote understanding and raise awareness of diabetes.
- To provide high quality, person-centred care and services.
- To help people with diabetes to be confident to self-manage and to be as independent as possible.
- To maintain a good quality of life for people with diabetes.

There are five levels of competency

- i. Unregistered practitioner
- ii. Competent nurse
- iii. Experienced or proficient nurse
- iv. Senior nurse practitioner or expert nurse
- v. Consultant nurse

The Framework sets out the topics involved in diabetes care and what competency is required by each of the above nurses for each topic.

This is so that the right health professionals are treating the right diabetes patients. For instance, practice nurses working at a basic level will be involved in screening for diabetes and complications and should be able to provide patient support, education, offer lifestyle advice and know when to refer on for specialist advice. By comparison, a consultant nurse in diabetes is a diabetes specialist nurse, often qualified to prescribe, to manage diabetes care and to train other health professionals.

New roles may be confusing

The number of nurses involved in different aspects of diabetes care has increased with the rise in the number of people with the condition and with the shift to diabetes being treated by GPs. The titles can be confusing and while we can't cover all of them, here's a few:

- **Diabetes Specialist Nurse [DSN]** – there is currently no single recognised qualification for a DSN. It is expected that all specialist nurses will have, or be working towards a degree level qualification and senior DSNs working towards a Masters degree. Changes in treatment and government directives have led many DSNs to specialise in certain areas of diabetes such as education or pump therapy.
- **Diabetes Facilitators** – these are usually based in primary care supporting and educating other health professionals to manage diabetes care effectively to try to achieve standardised care.
- **Consultant Nurse** – these are experienced nurses whose job incorporates education, leadership in planning services and research.
- **Practice nurses** – all practice nurses are registered nurses and they cover a wide range of clinical conditions. If they are involved in diabetes care, then they should be trained in diabetes and have a minimum of 6 to 12 months experience in diabetes care. There are growing numbers of practice nurses providing a high level of diabetes care and many are non-medical prescribers carrying out medicines reviews and issuing prescriptions.
- **Diabetes Care Technician** – this is an unqualified person who is suitably trained to carry out routine screening for diabetic complications.

Prescribing nurses

There are now 30,000 nurses in the UK who are able to prescribe from a limited list of medicines. These medicines are listed in the Nurse Prescribers' Formulary for Community Practitioners and they are mainly over-the-counter medicines and include wound dressings, laxatives and creams.

Added to this there are a further 19,000 nurses who are qualified as both independent and supplementary prescribers.

Independent prescribing nurses – are able to assess, diagnose and prescribe any licensed or unlicensed medicine within their area of competence eg a prescribing nurse who specialises in diabetes can prescribe for this condition.

Supplementary prescribing nurses – are able to prescribe after a doctor has assessed and diagnosed a patient's condition and a clinical management plan [care plan] has been drawn up with the patient. There is a list of medicines from which the supplementary prescribing nurse is able to prescribe. Supplementary nurse prescribers are often used for long-term conditions such as diabetes.

Both independent and supplementary prescribers are able to prescribe controlled drugs but the conditions are restricted.

Note: Appropriately qualified pharmacists are also able to prescribe using both independent and supplementary prescribing, as can optometrists for conditions that affect the eye. Other health professionals such as radiographers and podiatrists are only able to use supplementary prescribing ie within a patients care plan.

If it is unclear to you what qualifications your nurse has, just ask – they will be only too happy to explain.



Useful Information

NHS websites – few people have heard of them

According to a report for NHS Connecting for Health, few people in the UK have heard of the NHS's major public health websites. Here they are:

NHS Choices www.nhs.uk is a useful site with masses of information ranging from health topics to details about your hospitals and how they have been assessed.

HealthSpace www.healthspace.nhs.uk describes itself as “a free, secure online personal health organiser. It can help you to manage your health, store important health information securely, or find out about NHS services near you.” So you can keep track of your weight, blood pressure, cholesterol levels and medications and there is a calendar to keep track of your various appointments with doctors and dentists etc. If you choose to have a Summary Care Record [if available in your area!], it can be viewed through HealthSpace.

Easyhealth www.easyhealth.org.uk is a website from Mencap and provides health information that is easy to understand for people with learning disabilities.

People with learning disabilities can develop Type 1 diabetes and as there is a higher prevalence of obesity, undiagnosed Type 2 diabetes is common. There are various levels of learning disability and missed diagnosis of diabetes is not unusual, for a variety of reasons – staff assuming that the symptoms of diabetes are due to the learning disability or due to the person's own understanding of the symptoms and the inability to communicate these. Once diagnosed, it is not appropriate for people with learning disabilities to be given standard leaflets in a written format, they are not of much use if you can't read. Easyhealth has a wide range of leaflets with words and pictures to help and also to help health professionals who are supporting people with learning disabilities.

Note: there is a legal requirement to make ‘reasonable adjustments’ to services for people with learning disabilities in primary and secondary care. Offering standard care is not enough – it is a question of doing things differently to suit needs which involves flexibility. NHS Trusts can be prosecuted for not complying with this requirement.

NICE Guidelines related to diabetes:

- **Type 1 Diabetes**
www.nice.org.uk/Guidance/CG15
- **Type 2 diabetes – liraglutide [Victoza]**
guidance.nice.org.uk/TA203
- **Type 2 Diabetes**
www.nice.org.uk/Guidance/CG66
- **Pathways – brings together all connected NICE guidance on a topic and includes diabetes**
pathways.nice.org.uk
- **Quality Standards in Diabetes – the treatment and care which should be provided**
www.nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp
- **Type 2 Diabetes – newer agents**
guidance.nice.org.uk/CG87/Guidance/pdf/English
- **Type 2 Diabetes – Footcare**
www.nice.org.uk/Guidance/CG10
- **Diabetic foot problems – care in hospital**
www.nice.org.uk/Guidance/CG119
- **Diabetes (Type 1 & 2) – Long acting insulin analogues**
www.nice.org.uk/Guidance/TA53
- **Type 1 Diabetes– Allogeneic pancreatic islet cell transplantation for type 1 diabetes mellitus**
<http://guidance.nice.org.uk/IPG257>
- **Type 1 Diabetes– Autologous pancreatic islet cell transplantation for improved glycaemia control after pancreatotomy**
<http://guidance.nice.org.uk/IPG274>
- **Neuropathic pain**
www.nice.org.uk/CG963

- **Diabetes (Type 1 & 2) – Patient Education Models**
www.nice.org.uk/Guidance/TA60
- **Diabetes – Insulin Pump Therapy**
www.nice.org.uk/Guidance/TA151
- **Diabetes (Type 1 & 2) – Inhaled Insulin**
www.nice.org.uk/Guidance/TA113
- **Diabetes in pregnancy**
www.nice.org.uk/Guidance/CG63
- **Public Health Guidance, Prevention of Type 2 diabetes PH35**
<http://guidance.nice.org.uk/PH35>
- **Management of long-term sickness and incapacity for work**
www.nice.org.uk/Guidance/PH19
- **Public Health Guidance on Physical Activity**
www.nice.org.uk/media/368/C9/2009002PhysicalActivityChildren020209.pdf
- **Medicines Adherence**
www.nice.org.uk/media/033/BE/2009001MedicinesAdherence.pdf

If you do not have internet access, you can request a copy of the NICE guidelines from NICE:

National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA
Telephone: **0845 003 7780**

Alternatively, you can always contact IDDT: **01604 622837**

This chart (on the page below) is to remind you of the 9 tests which should be carried out at your annual review. You can keep a record of the tests and dates they were carried out by completing the date and ticking the box for each test. At your review, ask if all 9 tests have been carried out. If so, tick the box but if not, ask why not and if necessary ask for the tests to be carried out.

The 9 Key Tests

This chart is to remind you of the 9 tests which should be carried out at your annual review. You can keep a record of which tests were carried out by completing the date and ticking the box for each test. At your review, ask if all 9 tests have not been carried out, if not ask why not and if necessary, ask for the tests to be carried out.

| Date | Weight | Blood pressure | Smoking status | HbA1c | Urinary albumin | Serum creatinine | Cholesterol | Eyes | Feet |
|------|--------|----------------|----------------|-------|-----------------|------------------|-------------|------|------|
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