

epilepsy  
society

epilepsy  
charter



## epilepsy charter

This charter has been developed to explain your rights and what services you can expect as an individual with epilepsy.

In some cases, the charter lists your 'rights' – things that you are entitled to by law. For these we say '**you have a right to...**'

(These pages have a **dark purple** edge.)

In other cases, you may not have a legal right, but these are recommendations. For these we say '**you should...**'

(These pages have a **light purple** edge.)

Epilepsy Society is grateful to the following for their help and guidance on this leaflet.

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James MacDougall, Policy Unit, Department of Health

Words set in **black bold** are explained on pages 25 – 27.



This symbol means further information is available.

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# epilepsy charter

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## information sources for this charter

This charter includes information from the **NHS Constitution**, the **NICE\*** clinical guideline on epilepsy, the **Equality Act 2010** and the **information strategy** (see pages 25 – 26 for more information). This charter also represents the views of people affected by epilepsy who use Epilepsy Society’s services.

### How information sources apply to each country

The NHS Constitution and the information strategy cover England. In some cases, the information in this charter may not apply to how the NHS operates in Wales, Scotland and Northern Ireland.

 **For more about the NHS Constitution and the NHS in other UK countries visit [www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**

 **For more about the information strategy ‘The power of information’ visit [www.informationstrategy.dh.gov.uk](http://www.informationstrategy.dh.gov.uk)**

\*NICE is the National Institute for Health and Care Excellence. It publishes healthcare guidance for England and Wales. Northern Ireland’s Department of Health, Social Services and Public Safety uses NICE guidelines where relevant for Northern Ireland. For Scotland see the Scottish Intercollegiate Guidelines Network (SIGN) at [www.sign.ac.uk](http://www.sign.ac.uk)

 **For more about the NICE guideline visit [www.nice.org.uk/CG137](http://www.nice.org.uk/CG137)**

The Equality Act 2010 covers England, Scotland and Wales.

 **For more about The Equality Act 2010 visit [www.adviceguide.org.uk](http://www.adviceguide.org.uk) or [www.gov.uk](http://www.gov.uk)**

## after a suspected seizure you should be seen by an epilepsy specialist within two weeks

“All children, young people and adults with a recent onset suspected seizure should be seen urgently by a specialist.”  
NICE clinical guideline

‘Urgently’ means being seen within two weeks. For adults, a ‘specialist’ is a doctor with training and expertise in epilepsy; for children and young people this is a paediatrician with training and expertise in epilepsy. This is recommended so that suspected epilepsy can be diagnosed and appropriate management can be considered without delay. If a diagnosis cannot be confirmed, NICE recommends further investigations or a referral to **tertiary services**. If any tests would be helpful, these tests should be done within four weeks.

“All patients should receive high-quality care without any unnecessary delay.” Handbook to the NHS Constitution

The sooner epilepsy is diagnosed, the quicker you can start making decisions about treatment and management. Trying to get your seizures controlled as soon as possible means that hopefully you will have fewer, and they will have less impact on you physically and emotionally. As epilepsy can be difficult to diagnose, seeing a specialist who has training and expertise in epilepsy can help to get a diagnosis, and to discuss the most appropriate treatment options for you.

 **For more about the NHS Constitution visit**  
**[www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**

 **For more about the NICE guideline visit**  
**[www.nice.org.uk/CG137](http://www.nice.org.uk/CG137)**

## if your seizures are not controlled, or your diagnosis is not clear, you should be referred to tertiary care

“If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, children, young people and adults should be referred to tertiary services soon for further assessment.” NICE clinical guideline

‘Soon’ means being seen within four weeks. This means you should be referred to tertiary services or ‘tertiary care’ if:

- your seizures are not fully controlled (that is, you are still having seizures);
- your medication is not controlling your seizures; or
- there is the possibility that your diagnosis might not be right.

Tertiary care is provided by specialist hospitals or units that focus on specific care for different conditions. You have to be referred to these services by either your GP (**primary care**) or your local hospital or clinic (**secondary care**).

In tertiary care you should be seen by someone with expertise in epilepsy, and have access to investigations to help you.

This might include reviewing your diagnosis to see what kind of epilepsy and seizures you have, looking at what treatment you have already tried and how it worked for you, and to plan your treatment and management for the future.

The aim of managing epilepsy is to fully control your seizures (so that you don’t have any seizures), on the best treatment option for you with the least impact on your life.

## you have a right to appropriate treatment options, and should have a consistent supply of medication

“You have the right to drugs and treatments that have been recommended by NICE\* for use in the NHS, if your doctor says they are clinically appropriate for you.” NHS Constitution

This means that if the drug that is most suitable for your epilepsy is recommended by NICE, you should be able to receive it. This depends on:

- the drug being ‘clinically appropriate’ (that it is the right drug for your epilepsy, seizures and for you); and
- the drug has been through a health **technology appraisal**.

The NICE guideline for epilepsy lists anti-epileptic drugs (AEDs) that are recommended for different types of epilepsy and seizures, which have been recommended through health technology appraisals. There may be other drugs that have not been through an appraisal (for example, newer drugs), which may be useful for you.

“AED treatment strategy should be individualised, taking into account... any other medication being taken, any other medical conditions, your lifestyle and preferences.” NICE clinical guideline

When discussing a treatment plan with your specialist, they will identify the treatment best suited to your epilepsy and seizures (for example, some AEDs work better for certain types of seizures than others). However, they should also take into account your overall health (such as whether you take drugs for any other condition), lifestyle and preferences. For example, some AEDs might make you feel tired so they might be best avoided if you are working or studying.

\*recommended by a NICE technology appraisal (see page 26).

## Consistency of supply

Most AEDs have two names, a generic name (for example carbamazepine) and a brand name given by the manufacturer (for example Tegretol). Some AEDs have more than one generic version, each of which can be given its own name.

For some AEDs, different versions of the drug can vary slightly and this could affect seizure control. Once you and your doctors have found an AED which helps control your seizures, and which suits you, it is recommended that you take this version consistently with every prescription (called 'consistency of supply'). If a prescription only has the generic name, a pharmacist can give any version of that drug. However, if the prescription has the brand name, the pharmacist has to give that brand of AED. You can ask your GP or neurologist to specify the version you need by writing it on your prescription.

Some drugs are made abroad and brought into the UK, or are made in the UK, exported and then brought back to the UK. These are called 'parallel imports'. They are sometimes labelled in a different language or have different packaging from usual. If you are concerned about taking parallel imports, you can ask your doctor to write 'no parallel imports' on your prescription. Although pharmacists don't *have* to follow this, many will try to ensure that you are happy about your medication. It can be useful to get your prescriptions from the same pharmacist each time, as they may keep patient records and be able to help with any queries.



**Download a letter for your neurologist, GP or pharmacist about consistency of supply at [www.epilepsysociety.org.uk/gettingtherightmedication](http://www.epilepsysociety.org.uk/gettingtherightmedication)**



**For more about generic and branded AEDs visit [www.epilepsysociety.org.uk/genericandbranded](http://www.epilepsysociety.org.uk/genericandbranded)**

## you are entitled to free prescriptions

You are entitled to free prescriptions for your anti-epileptic drugs and for any other prescriptions you have.

This is referred to as 'medical exemption' from paying prescription charges. To apply for a medical exemption certificate (or 'MedEx'), you need to complete an FP92A form from your GP surgery. This needs to be signed by your GP or hospital doctor. The certificate lasts for five years, and then you need to renew it.

The certificate means that all medications that you get on prescription will be free of charge, whatever they are for (not just your anti-epileptic drugs).

A MedEx form is not needed in Scotland, Wales and Northern Ireland as all prescriptions are free in these countries.



**For more about MedEx certificates visit: [www.nhs.uk](http://www.nhs.uk) and search for 'free prescriptions'.**

## you have a right to be involved in your healthcare...

**...and you should have enough information, and the appropriate support, so that you can make informed decisions about your health and be an active participant in all decisions about your epilepsy treatment and management.**

“You have the right to be involved in discussions and decisions about your health and care, and to be given information and support to enable you to do this.” NHS Constitution

“Healthcare professionals should adopt a consulting style that enables the [person with epilepsy], and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific needs.” NICE clinical guideline

You should be as actively involved as you want to be in all discussions and decisions about your health and epilepsy management. This includes being given enough information to make informed decisions about your care, at the time you need the information, and presented in a way that is useful for you so that you can understand how it affects you individually.

NICE provides ‘Pathways on epilepsy’ – interactive topic-based diagrams which aim to enable you and your healthcare professionals to quickly view and navigate all NICE guidance recommendations on the care of someone with epilepsy.

 **To find the NICE pathways on epilepsy visit [pathways.nice.org.uk/pathways/epilepsy](https://pathways.nice.org.uk/pathways/epilepsy)**

Your healthcare professionals should make sure you have the information you need, and support you to make decisions. Having information about epilepsy is important, but you also need to be able to consider how this applies to your specific situation, so that you can make the right decisions for yourself.

For example, making an informed decision about whether to start treatment with medication means having information about the options available, including the risks and benefits of taking or not taking medication, and time to consider your decision.

Your situation, and your choices about treatment and care, may change over time. It is important that you are given information and support to make decisions as your situation changes. In some situations, it might be appropriate for you to be referred back to services, or to new services, if they are better suited to meet your needs.

For example, when young people reach 'transition' (usually at around 16 – 18 years of age) they should be supported in moving from paediatric services to adult services. Women with epilepsy, who have been under the care of their GP if their epilepsy is well controlled, should be referred to a neurologist if they are planning a pregnancy.

Both the NHS Constitution and NICE guideline recognise the importance of involving your family and carers in helping you to make informed decisions, if you would like them to.

### **Information for you**

Information is important throughout your epilepsy diagnosis, treatment and management. Your healthcare professionals might use checklists of topics that you might want information on, or to discuss. This includes information about:

- epilepsy, including specific information about *your* epilepsy;
- seizures, including *your* seizures, and possible seizure triggers;
- treatment options including medication or surgery, depending on your type of epilepsy;
- any relevant issues around education or employment, depending on your age;

- practical issues such as driving, benefits and financial support;
- lifestyle issues such as leisure activities, alcohol, and sleep;
- self-management issues such as looking after yourself;
- emotional and psychological issues such as the impact on memory and mood; and
- risk and ways of reducing risks, accidents and injuries, and first aid for seizures. Some people with epilepsy have status epilepticus (prolonged or repeated seizures) and it is possible, although not common, to die due to epilepsy. So information on sudden unexpected death in epilepsy (SUDEP) may be appropriate, depending on what your epilepsy is like and how it affects you.

Other issues might be relevant for particular individuals. For example, information around contraception and pregnancy for girls and women.



**For more about the NHS Constitution visit**  
[www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)



**For more about the NICE guideline visit**  
[www.nice.org.uk/CG137](http://www.nice.org.uk/CG137)

## you should have a comprehensive care plan...

**...agreed with your healthcare professionals, which should include both medical and lifestyle issues. You should also have an annual review of your epilepsy.**

Everyone with epilepsy “should have a comprehensive care plan... agreed between the person, family and/or carers where appropriate, and primary and secondary care providers.

This should include lifestyle issues as well as medical issues.”

NICE clinical guideline

A care plan for your epilepsy should be like a ‘road map’ of your condition, and its treatment and management. It should have information about your epilepsy and seizures, and your treatment, including what treatment you are on, any treatments you are starting or what might be considered in the future.

The care plan should also cover other issues that may be important to you, such as education, work, driving, leisure activities and starting a family. This depends on your situation and your wishes and hopes for the future.

The care plan should be made by you and your healthcare professionals together. You might want to involve your family, carers or anyone else important to you, as they may help you to make decisions about your epilepsy. Developing a care plan together means that you can make informed choices about your epilepsy, and know what to do if things change over time. Your plan should be reviewed and updated when needed.

Everyone with epilepsy “should have a regular structured review. For adults this should be at least yearly and with their GP or a specialist. For children this should also be at least yearly, and be with a specialist.”  
NICE clinical guideline

You should be offered a regular review with either your GP or your specialist (depending on how your epilepsy is). The review should look at your epilepsy, how it is managed and your care plan. It should also include leisure and lifestyle issues, and be an opportunity for you to discuss any other issues that are important to you at that time.

 **For more information about epilepsy reviews visit [www.epilepsysociety.org.uk/yearlyreview](http://www.epilepsysociety.org.uk/yearlyreview)**

If your epilepsy is not well controlled, your doctor may suggest that a referral would be helpful. This might be to a specialist in secondary care (hospital) or tertiary care (a specialist hospital) to help improve your epilepsy management. They may also suggest that a referral to other support services might be helpful, such as to an occupational therapist.

 **For more about the NICE clinical guideline visit [www.nice.org.uk/CG137](http://www.nice.org.uk/CG137)**



## you have a right to choose who provides your care

“You have the right to make choices about the services commissioned by NHS bodies and to information to support these choices.”  
NHS Constitution

When you are referred for a first outpatient appointment (where you do not stay in hospital overnight) with a service led by a consultant, you have the right to choose where you go (such as the hospital you go to). This does not include emergency admissions (such as going to A&E).

You can find information to help you decide where you would like to go, on the NHS Choices website. This includes information on the services offered by different hospitals.

 Visit [www.nhs.uk](http://www.nhs.uk)

Some GPs offer a service called ‘Choose and Book’. This is an electronic referral system which allows you to choose which hospital you want to go to, from any NHS hospital in England (including some private hospitals). You can see information about each hospital, and book the date and time of your appointment, online.

 For more information about Choose and Book visit [www.chooseandbook.nhs.uk](http://www.chooseandbook.nhs.uk)

## **You can ask for a second or ‘further’ opinion**

Although you do not have a legal right to *receive* a second (or ‘further’) opinion, you can *ask* your GP or hospital doctor or consultant to be referred to another doctor for their opinion on your health condition.

You might want a second opinion about your health condition, your diagnosis or your treatment options. If you talk to your current doctor about why you feel a second opinion would be helpful, they may be able to answer any questions you have or explain anything you are not sure about. If you still feel that you want a second opinion, you can ask your GP to refer you either to another GP, or for a re-referral to another hospital doctor. The person you are referred to will know that you have been referred for a second opinion, and will usually have access to any results from tests that you have already had.

You might also find that your GP or doctor asks a colleague to give a second opinion if they feel it would be helpful.



**For more about asking for a second opinion visit [www.nhs.uk](http://www.nhs.uk) and search for ‘second opinion’.**



**For more about the NHS Constitution visit [www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**

# you have a right to access your own health records

“You have the right of access to your own health records.”

“The NHS commits to share with you any letters sent between clinicians about your care.”

Handbook to the NHS Constitution

If you would like to see your health records, you can ask your clinician (GP or hospital doctor) about this. Your doctors might already copy you in on letters (such as letters after your appointments or referral letters), or you can ask them to if they don't already do this. Being able to see your health records, and any letters about your care, might help you to understand more about your health. It might also help when making decisions about your healthcare, and being able to discuss with your doctors any questions or concerns you have.

Although you have a legal right to access your health records, sometimes you will be charged for this.

The Government's **information strategy** (launched in 2012) is a 10-year plan for improving information in the NHS. The strategy includes an aim that everyone should be able to access their GP records, including test results, online by 2015. The strategy also says that all confidential information in healthcare records must be kept safe and secure, and only used appropriately. It also means that health records are shared appropriately with professionals who might be involved in your care, so that they can offer the best treatment and management of your condition.

 **Find out more about the information strategy 'The power of information' at [www.informationstrategy.dh.gov.uk](http://www.informationstrategy.dh.gov.uk)**

 **For more about the NHS Constitution visit [www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**

# you are entitled to ask for a social care needs assessment

**Anyone caring for you is also entitled to an assessment of their needs. You may also be entitled to benefits.**

If you are over 18 years of age you can ask for a social care needs assessment (or 'community care assessment') to see if you are eligible for help with care or support. This assessment looks at what difficulties or challenges you have due to your condition, and what help or support might be useful to overcome these. Local authorities have a duty to provide assessments to people who need them.

An assessment of your needs might help to identify what you need or would find helpful, what is available to you locally, and what you might be eligible to get financial help with. Assessments look at what is important to you, any health conditions you have and how they affect you, and what you would like to achieve, now and in the future. They include different aspects of your life such as daily living and practical tasks, being part of your community, and managing risk.

The assessment might include:

- doing a risk assessment of your living arrangements to see if any equipment or adaptations might be helpful, such as a seizure alarm, furniture protection or a shower;
- whether you might benefit from having extra support, such as a carer or personal assistant, at home or when you go out; and
- whether you meet the criteria for a personal budget (which you can use to pay for any help or care that you need).

Having an assessment does not mean that you are automatically entitled to help. What help you can get depends on your needs (how your epilepsy affects you) and your financial situation.

Assessments will usually identify whether you have ‘critical’ or ‘substantial’ needs. Your local authority may meet some of your needs (depending on their criteria for funding). If your local authority is not able to fund meeting your needs, you will usually be told what services and help are available, but you would have to fund these yourself.

Assessments are arranged through adult social care or social services from your local authority. You can either contact your local authority direct, or ask your GP to refer you.

 **To find your local authority and see whether you meet their eligibility criteria, visit [www.gov.uk](http://www.gov.uk) and search for ‘needs assessment by social services’.**

### **Unpaid carers are entitled to their own assessment**

If you have someone who cares for you (such as a family member or friend who helps you in an unpaid capacity) they are entitled to an assessment from social services to identify help or support needs for themselves. This might include the need for home help, equipment, or for respite care. Under the Care Act 2014, local authorities have a legal duty to provide services to carers, if their ‘carers assessment’ shows that they have support needs that fit the authority’s criteria.

If you have an assessment through your local authority, your carer should already have been told about their right to an assessment. If you haven’t had an assessment, your carer can still ask for their own assessment by contacting the local authority directly and asking for one.

 **For more about carers, visit [www.epilepsysociety.org.uk/carers](http://www.epilepsysociety.org.uk/carers)**

 **For carers assessments visit [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)**

## **People with epilepsy, and carers who care for them in an unpaid capacity, may be entitled to welfare benefits**

People with epilepsy may be entitled to benefits, depending on how their epilepsy affects them. For example, Disability Living Allowance (DLA – for children under 16 years), Personal Independence Payment (PIP – which started to replace DLA for working-age people from 2013) and Attendance Allowance (AA – for people over 65) are benefits that do not depend on your income, or whether or not you work. To be eligible for these benefits you need to have daily living or care needs, or mobility needs.

Some carers can claim Carer's Allowance. This benefit depends on their income and savings and is usually paid to people between the ages of 16 and 65, who spend at least 35 hours a week caring. For your carer to be entitled to Carer's Allowance, you must get Attendance Allowance, Disability Living Allowance or Personal Independence Payment.

 **For more about benefits, visit the benefits section on our website: [www.epilepsysociety.org.uk/benefits](http://www.epilepsysociety.org.uk/benefits)**

 **Information on benefits is also available from your local Citizens Advice Bureau, or by visiting [www.turn2us.org.uk](http://www.turn2us.org.uk) or [www.gov.uk](http://www.gov.uk)**

 **For more about what other help is available, visit [www.epilepsysociety.org.uk/helpavailable](http://www.epilepsysociety.org.uk/helpavailable) and [www.epilepsysociety.org.uk/supportforcarers](http://www.epilepsysociety.org.uk/supportforcarers)**

# you have a right to be treated with dignity and respect and to not be discriminated against

“You have the right to be treated with dignity and respect, in accordance with your human rights.”

“You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.” NHS Constitution

Your nurse or midwife is...respectful, putting care and safety first. They help and encourage you to take part in decisions about your care...and help you to access the care and support that you need.

Your nurse or midwife listens to you and takes note of concerns. They respect your right to privacy and confidentiality”

Good care from nurses and midwives:

What our professional Code means for you, 2015

...make sure that any discriminatory attitudes and behaviours towards those receiving care are challenged.

The Code for Nurses and Midwives, 2015

As well as the above rights and professional codes in NHS services, the **Equality Act 2010** protects people from discrimination, including on the basis of disability.

Under the Equality Act, someone has a disability if they have “a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities”. Epilepsy is a physical, long-term condition. People with epilepsy are protected under the Equality Act even if their seizures are controlled or if they don’t consider themselves to be ‘disabled’.

The Act covers healthcare, education, employment, and access to goods and services, such as shops, banks and public transport.

Under the Equality Act 2010, you do not have to disclose that you have a disability or that you are a carer for someone who does. However, if you do tell people this, for example an employer, they can make sure they treat you fairly, and avoid various different types of discrimination, including:

- perceived discrimination – treating someone unfairly by assuming that they have a disability, and that this will affect their ability to carry out day-to-day activities (for example, assuming that a person’s epilepsy will mean they can’t do a job as well as someone without epilepsy);
- associative discrimination – treating someone unfairly because they are connected to someone else with a disability. If you have a carer (see page 19) they are protected against any discrimination due to their association with you. For example, not being promoted at work because they are also your carer;
- indirect discrimination – treating everyone the same in a way that puts someone with a disability at a disadvantage (for example, a rule that ‘everyone must use the stairs’ is unfair for people who use wheelchairs); and
- discrimination arising from disability – treating someone unfairly because of something connected with their disability (for example, telling someone with a visual impairment they can’t bring their guide dog to work, without a justifiable reason).

 **For more about The Equality Act 2010 visit**  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk) or [www.gov.uk](http://www.gov.uk)

 **For more about employment and epilepsy visit**  
[www.epilepsysociety.org.uk/employment](http://www.epilepsysociety.org.uk/employment)

 **For more about support for carers visit**  
[www.epilepsysociety.org.uk/carers](http://www.epilepsysociety.org.uk/carers)

 **For more about The Code for nurses and midwives, visit**  
[www.nmc.org.uk/standards](http://www.nmc.org.uk/standards)

## you have a right to complain about services or treatment

You have a right to complain about NHS services you receive and “the right to have any complaint you make about NHS services acknowledged within three working days and to have it properly investigated...to be kept informed of progress, and to know the outcome of the complaint”.

NHS Constitution

If issues can be resolved without needing a formal complaint, by speaking to someone on site, or to a manager related to the service, this may be quicker and less stressful for you.

If you have a complaint about any NHS treatment or service, you can make your complaint at the point you receive care either to the NHS service involved, or through the hospital’s PALS (Patient Advice and Liaison Service). You can ask for a copy of their complaints procedure. Or you can complain to the relevant clinical commissioning group (CCG). If your complaint is not resolved, you can take it to the Parliamentary and Health Service Ombudsman (see [www.ombudsman.org.uk](http://www.ombudsman.org.uk)) or for a social care provider, to the Local Government Ombudsman (see [www.lgo.org.uk](http://www.lgo.org.uk)).

NHS Choices has more information about the NHS complaints procedure. There are also procedures if you are not satisfied with the outcome of any complaint, or if you feel you have been affected or harmed by treatment.

 **For more about PALS visit [www.pals.nhs.uk](http://www.pals.nhs.uk)**

 **For more about NHS Choices or to find your local Clinical Commissioning Group (CCG) visit [www.nhs.uk](http://www.nhs.uk)**

 **For more about the NHS Constitution visit [www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**

# you have responsibilities as well as rights

Along with your rights to services from the NHS, you have some responsibilities to the NHS too.

These include the following:

- “please recognise that you can make a significant contribution to your own, and your family’s, good health and wellbeing, and take personal responsibility for it;
- please provide accurate information about your health, condition and status;
- please keep appointments, or cancel within reasonable time. Receiving treatment within the maximum waiting times may be compromised unless you do;
- please follow the course of treatment which you have agreed, and talk to your clinician if you find this difficult; and
- please give feedback – both positive and negative – about your experiences and the treatment and care you have received, including any adverse reactions you may have had”.

Handbook to the NHS Constitution



**For more about the NHS Constitution, and your responsibilities, visit [www.nhs.uk/NHSConstitution](http://www.nhs.uk/NHSConstitution)**



## documents and organisations

### **The information strategy: ‘The power of information’**

The information strategy is the Department of Health’s framework for gathering, storing and sharing information for, from and about people using health and social care services. The strategy aims to ensure that information is used to improve our experiences of health and social care and improve the quality of services. For example, accessing your GP records and booking appointments online, and having more information so that you can choose the treatment and services that are right for you.

**For more about the information strategy ‘The power of information’ visit [www.informationstrategy.dh.gov.uk](http://www.informationstrategy.dh.gov.uk)**

### **The NHS Constitution**

The NHS Constitution aims to set out clearly what patients, the public and staff can expect from the NHS and what the NHS expects from them in return. The constitution includes rights (what you can legally expect), pledges (what the NHS is committed to achieving) and responsibilities (to and from patients, the public and staff). The constitution aims to ensure better treatment within, by and of the NHS. The constitution applies to everyone who is entitled to NHS services in England.

**A handbook to the NHS Constitution can be found at [www.gov.uk/government/publications/the-handbook-to-the-nhs-constitution-for-england](http://www.gov.uk/government/publications/the-handbook-to-the-nhs-constitution-for-england)**

## The Equality Act 2010

The Equality Act 2010 combines nine anti-discrimination laws (including the Disability Discrimination Act) into a single law. It protects people from unfair discrimination, and promotes equal opportunities. It also protects people, such as carers, who are associated with another person, from discrimination.

 **For more about The Equality Act 2010 visit**  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk) or [www.gov.uk](http://www.gov.uk)

## NICE – National Institute for Health and Care Excellence

NICE is the organisation that publishes national guidance and standards on the promotion of good health and the prevention and treatment of ill health. It produces guidelines on different health conditions, including the clinical guideline ‘The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care’. This guideline was updated in January 2012.

Although ‘guidance’ (and not ‘the law’), NICE clinical guidelines give best practice advice, are produced by experts in the topic, and all their information and recommendations are thoroughly researched and based on the best available evidence.

NICE also publishes ‘**technology appraisal**’ guidance (TAs). This type of guidance evaluates the clinical and cost effectiveness of different medicines, tests or devices, so that patients receive the best treatments and the NHS makes the best use of its resources. Single TAs look at one ‘technology’, and multiple TAs compare several. They are often done for new treatments so that they can be recommended within the NHS. NICE uses evidence for the appraisal, which is reviewed and evaluated by an independent review group to look at the benefits and costs.

 **To find the NICE pathways on epilepsy visit**  
[pathways.nice.org.uk/pathways/epilepsy](http://pathways.nice.org.uk/pathways/epilepsy)

## terms used in this charter

**Primary care** – health services such as the GP or pharmacy.

This is ‘primary care’ because it is usually the first place you will go to for help with anything medical.

**Secondary care/secondary services** – health services such as local hospitals and clinics, where you would see someone more specialised than the GP or pharmacist, such as a neurologist.

This is ‘secondary care’ because you usually have to be referred by your GP. It also includes A&E departments.

**Tertiary care/tertiary services** – specialist hospital or unit that focuses on specific care for different conditions. For example, if someone is being considered for epilepsy surgery, they might be seen in tertiary care. You have to be referred to tertiary care from either primary or secondary care.

Every effort is made to ensure that all information is correct. Please note that information is intended for a UK audience and may change after printing.

This information is not a substitute for advice from your own doctors.

Epilepsy Society is not responsible for any actions taken as a result of using this information.

## cares

A full life for everyone affected by epilepsy.

## listens

**confidential helpline** 01494 601 400

Monday to Friday 9am to 4pm, Wednesday 9am to 8pm.

National call rate. Information and emotional support.

## informs

Website, leaflets, DVDs – call 01494 601 392.

## connects



Forum, app, Facebook, Twitter and YouTube.

Volunteer, become a member, fundraise.

## educates

Awareness, training for professionals.

## researches

Pioneering medical research.

## campaigns

Shaping the future of epilepsy.

## understands

Medical and care services.

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Epilepsy Society is the working name of The National Society for Epilepsy  
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