Getting the best from neurological services

A guide for people affected by conditions of the brain, spine and nervous system

What help is available to me?

Where can I find out more?

What will happen to me?
The first edition of this booklet was written by Lynda Young and published by the Neurological Alliance in May 2003 following extensive consultation with people with neurological conditions, their carers, the charities that represent them and the professionals who work with them.

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The Neurological Alliance is a collaborative forum of a wide range of neurological charities. The Alliance campaigns for the highest standards of service and care for the millions of people in the UK with a neurological condition.
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Part 1
Services for people with neurological conditions

What help is available to me?

‘I only wish such a guide had been available when I was first diagnosed’ Person with dystonia
Introduction

Who is this booklet for?
If you have recently been diagnosed with a neurological condition you may be experiencing all sorts of feelings. You may also be very concerned if it is one of your friends or family who has received a diagnosis. You may not be too sure where to find help. This booklet highlights what support is available if you need it. It has been produced in consultation with people who have neurological conditions. It provides answers to questions frequently asked by them.

This booklet is designed for people living in England. Services may be organised differently elsewhere. However it may also be relevant to you if you live in other parts of the UK.

It describes how some people experience neurological services. However everyone’s situation will be unique. The help you receive will depend on your condition, how it occurs, and the organisation of services within your area.

How to use this booklet
This booklet is for you to read when you wish. As you may not want to read all of it at one time, it is designed in a question and answer format. You can therefore look at the questions that concern you now. If you want to know where to go for more advice about a particular issue the side notes will help you. Words printed in bold are explained further in the glossary in Part 3. All contact details are listed in Part 3.

What is a neurological condition?
Approximately 10 million people across the UK have a neurological condition; a result of damage to the brain, the spinal cord and other parts of the nervous system. Some conditions are present from birth (congenital), others are caused by illness or injury. These account for 20% of acute hospital admissions and are the third most...
common reason for seeing a GP. There are many hundreds of neurological conditions. Some are relatively common, for example stroke and multiple sclerosis, whilst others such as narcolepsy and ataxiatelangiectasia are rare.

All of the charities listed at the end of this booklet can help people with neurological conditions. If your condition is not there please contact one of the charities listed under ‘all neurological conditions’. They will be able to suggest the charity most suited to your needs.

**Information about the National Service Framework for long term conditions**

In March 2005, the Department of Health launched a policy document called the National Service Framework (NSF) for long-term conditions. The framework aims to transform health and social care services for people with neurological conditions. This will be achieved by providing these people with access to a faster diagnosis, more rapid treatment, and a comprehensive package of care. The NSF sets out a list of 11 quality requirements in the services offered to people with long term neurological conditions, and will be referred to in relevant sections of this booklet. The NSF applies to England only.

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**Services for people with neurological conditions**

**What services are available to me?**

If you have a neurological condition you may need a range of services to support you and your family. Quality requirement one of the NSF states that people with long term conditions are to be offered integrated assessment service.
and planning of their health and social care needs. Some conditions are ongoing and you may want long-term support. Many of these services will help maintain and improve your quality of life. It is therefore important for you to know how to access to them.

Whilst services will often be available when you need them, at times it may take a while for services to be arranged. It is therefore important to ask as soon as, or even before, if you need help. You may have to ask more than once and obtain advice from more than one person.

You will not have to pay to use most of the services described in this booklet. However you may wish to pay privately for some services and you may be asked to provide a contribution towards others.

You may wish to use some or all of the following services.

**National health services**

The NHS has Primary Care Trusts and NHS Trusts. Your Primary Care Trust is responsible for your general practitioner (GP) and other staff, such as community nurses, operating from your GP’s practice or health centre. Primary Care Trusts also run community rehabilitation services using physiotherapists, occupational therapists, and speech and language therapists.

The second quality requirement of the NSF places emphasis on prompt access to specialist neurological expertise (as close to home as possible) for a person suspected of having a neurological condition. As well as primary care services, your NHS Trust provides hospital-based services, including outpatient services and will be linked to a number of Primary Care Trusts. It is responsible for your local district hospital, neurology centre, neurorehabilitation unit and neurosurgery
centre. NHS Trusts also sometimes run specialist units for some of the common neurological conditions, for example stroke units and multiple sclerosis clinics. There are also specialist clinics, for example pain clinics. Access to high quality rehabilitation services in hospitals or other specialist settings comes under the fourth quality requirement of the NSF, which states that people with neurological conditions should receive the help they need before returning home for ongoing community rehabilitation and support.

**Social services**

According to the eleventh quality requirement, people with long-term neurological conditions should have their specific neurological needs met while receiving treatment or care in any health or social care setting. Councils provide community care services, usually through social services departments. Services available can include:

- help with personal care
- meals on wheels
- laundry services
- equipment and aids to use in your home
- free or subsidised travel on public transport.

You may have to meet certain criteria to be eligible for these services and you may have to pay for some of them. A community care assessment is undertaken by a social worker/care manager to find out your needs.

If you need help you can contact your social services department and request an assessment from them. Their details are listed in your local telephone directory. Your GP, specialist and others involved in your care may also advise you about contacting social services.

After your assessment your social worker/care manager will draw up a copy of a care plan, which summarises the services to be provided. You will be given a copy of
this and it should be reviewed by social services every year. In some areas you may be under the care of a social worker from a specialist social services disability team.

**Equipment services**

The 2006 white paper: *Our health, our care, our say* states that people with long term conditions should receive timely, appropriate assistive technology and equipment to support them to live independently, help them with their care, maintain their health, and improve their quality of life.

The Government intends that in the future there should be one point of contact for you to request all your equipment needs. However, at present equipment may still be provided from a variety of sources in your area. The table below gives you examples of equipment available and how it can be obtained.

<table>
<thead>
<tr>
<th>Equipment/service required</th>
<th>Available from</th>
<th>Referred by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily living equipment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>eg. equipment and household gadgets</td>
<td>Social Services Department</td>
<td>Social Worker, self referral</td>
</tr>
<tr>
<td><strong>Adaptations to your home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>eg. stair lifts, making it easier to use the bathroom</td>
<td>Social Services Department</td>
<td>Social Worker, Occupational Therapist, self referral</td>
</tr>
<tr>
<td><strong>Mobility equipment</strong></td>
<td></td>
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<tr>
<td>eg. wheelchairs</td>
<td>a: the wheelchair service at your local hospital trust or b: your local wheelchair distribution centre</td>
<td>a: Physiotherapist at local hospital, Community physiotherapist via a referral from your GP; b: Occupational therapist or self referral</td>
</tr>
<tr>
<td><strong>Home nursing equipment</strong></td>
<td></td>
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<tr>
<td>eg. pressure relief mattress</td>
<td>Community nurses</td>
<td>GP</td>
</tr>
<tr>
<td><strong>Equipment for employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>eg. support workers if someone needs help at work</td>
<td>Disability Employment Adviser at your local Job Centre</td>
<td>Self referral, employer</td>
</tr>
</tbody>
</table>
You cannot usually get financial help after you have already started a building adaptation or bought an item of equipment, therefore you should apply before making any purchases.

**Financial support**

You and your carers may qualify for state benefits. If it is your child who has a neurological condition they may qualify for benefits in their own right. Depending on your circumstances, financial help may be available:

- for help to look after yourself
- for help getting around
- if you are unable to work
- towards the rent
- towards paying for prescriptions. Prescription exemption forms are available from your GP’s surgery.

Benefits may also be available for people who work and for students. Some benefits, for example the disability living allowance, are paid on top of any other income and benefits.

Any medical condition which prevents you from holding and handling phone books qualifies you for a free directory enquiries service. This applies to a number of neurological conditions. Phone 195 and ask to be registered for the free directory enquiries service.

It is important to apply for state benefits as soon as possible as applications cannot be backdated. As benefits and allowances often change please ensure that any information you have about them is up to date.
You can find details of local support groups from the charities listed at end of this booklet.

Your GP, local social services department, public library, local council for voluntary service and local hospital may have details about local groups. They may also be listed in your local phone book under ‘charitable and voluntary organisations’. Or you may find the ‘community and living’ section of your council’s website helpful.

‘Some conditions are best treated at specialist centres so you need to contact the support group/charity first to find out if they exist.’

Person with neurofibromatosis type 2

Charities
Charities provide a wide range of services for you, your family, carers and friends. Typically they can:

— provide information about your condition and the help available to you. Many have staff with expert knowledge of particular conditions.
— give support and guidance by telephone to anyone who calls. Some organisations operate helplines, for you to discuss your condition. Phone numbers for helplines are listed in Part 3 of this booklet.
— link you to local support groups where you can share personal experiences and receive practical support and advice.
— advise you on the best course of action to obtain all the help you need.

The inclusion of high quality and timely information as an important component of person-centered services is part of quality requirement one of the NSF.

Employment services
According to the NSF, people with long term conditions are to have the access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

Disability employment advisers located at your local job centre provide specialist advice and support concerning all aspects of employment.

If you are employed when diagnosed with a neurological condition, assistance is available to help you stay in your job. The access to work scheme run by the employment service can support you, for example by providing funding for alterations to the workplace and towards transport to work.
The Disability Discrimination Act gives people with a disability, or former disability, the right not to be discriminated against by an employer. Some people with neurological conditions will be covered by this Act.

**Expert Patients Programme**

The Expert Patients Programme is an NHS initiative which provides training opportunities for people with chronic conditions, which includes neurological conditions. It is described as a self-management course giving people the confidence, skills and knowledge to manage their condition better and be more in control of their lives.

**Sources of Advice**

To find out more including contact details of Expert Patient staff in your area, you can visit the Expert Patients Programme website www.expertpatients.nhs.uk
Part 2

Stages in the management of a neurological condition

- Onset
- Awareness
- GP visit
- Referral
- Consultation
- Diagnosis
- Treatment and management
Onset and diagnosis

What will happen when I see my GP?
You can experience the onset of a neurological condition at any time in your life. Some neurological conditions are diagnosed and treated by your GP. For other suspected neurological conditions your GP may wish to refer you to a specialist. Prompt access to a specialist is a requirement of the NSF. You can ask to be referred to a particular specialist but you should have a reason for doing so. Your GP may also continue to be involved in the ongoing management of your condition.

How long will I have to wait?
Many people will see a specialist within a couple of months. The maximum waiting time specified by the Government from referral to the date of your first outpatient appointment with a specialist should be 13 weeks.

What can I do if I am still waiting for a diagnosis?
You may be given an initial diagnosis and then a confirmed diagnosis when all the tests have been completed. If you have to wait a long time for a diagnosis this should not delay you in accessing any services you need. If you need help with everyday living you can either speak to your GP or to social services.

Questions to consider asking your GP about referral to a specialist

- Would it help to see a specialist?
- Can I be referred to a specialist?
- To which specialist am I being referred?
- What is he/she a specialist in?
- Where will I see the specialist?
- Am I being treated as an urgent referral?
- How long am I likely to have to wait to hear from the hospital?
- How long am I likely to have to wait for the appointment?
- Are there any services I would benefit from whilst I am waiting for a diagnosis?
- Is there any written material available?
- Are there any tests I need to undertake before my appointment?
When you have the diagnosis it feels like being sent to a foreign country, you don’t know the language or where to get help.’
Carer of a person with motor neurone disease

What happens if I require urgent treatment?
There may be circumstances where you need an urgent diagnosis and/or urgent treatment. You should go through your GP or, if this is not possible, your local accident and emergency department. According to the NSF, people needing hospital admission should be assessed and treated in a timely manner by teams with the appropriate skills and facilities.

You may be admitted to hospital for treatment and tests. If an ongoing neurological condition is suspected then you can be referred to specialist neurological services for diagnosis and further treatment.

What will happen at my hospital appointment?
Your specialist will explain the process of making the diagnosis. This will include the range of tests to be carried out, where and when they will be carried out and how long it is all likely to take. Three of the most common tests for neurological conditions are an Angiogram, a CT Scan and an MRI Scan.

You should feel free to bring someone with you to all your hospital appointments. If English is not your first language you can ask, in advance of your appointment, if your hospital can provide an interpreter. Ask if there is any written information in your language or any organisations that can help.

What type of information can I expect to receive from my specialist?
Your specialist will explain about your diagnosis, possible treatment options and the benefits and any risks of each treatment. You can also ask if there is any written information for you and your family to take away and read. The information provided should let you know about the implications of your diagnosis and treatment for your education and employment, if that is relevant to you.
Questions to consider when asking about treatment options

What are the different types of treatment options?

What if the treatment doesn’t work?
Will I have to spend time in hospital?
How often will I need treatment?
How long will my treatment last?

How long can I take to decide what treatment I have?

How will I feel during my treatment and are there any lasting side effects?
Will I be able to continue my current lifestyle?
Are my children at risk of developing this condition?

What is the likelihood of success of the treatment?

When will I know if the treatment has worked?

Who will manage my treatment?

Will the treatment or the condition affect my ability to drive?
Can I still work?
Can I be included as part of a clinical trial?

People often have difficulty absorbing all the information they receive at diagnosis. You can ask for someone to be available to discuss your diagnosis and its implications with you afterwards. This can be either by telephone or at another appointment. In some instances there will be a specialist nurse for you to speak to.

What is a clinical trial?
You may be asked to take part in a clinical trial or you may wish to offer to do so. Clinical trials assess the effectiveness and possible side effects of a new treatment before it is widely used. During a trial you will be closely observed. Any information recorded will be treated in the strictest confidence. It is your choice whether you participate or not. You can withdraw from a trial at any time without affecting your overall treatment.

How are rare conditions diagnosed?
Some neurological conditions are very rare. This means that you may not get a confirmed diagnosis immediately. It may sometimes be necessary for you to be referred to another specialist with different expertise. In these instances your first specialist will either refer you or advise your GP to make a second referral.

The NSF advises that people should have access to specialists and treatment as close to home as possible.
driving
If your specialist has said that you may not drive you must inform the Driver Vehicle and Licensing Agency (DVLA). You must also tell them if you have been told your condition may affect your ability to drive.

DVLA Drivers’ Medical Unit
DVLA Longview Road
Swansea SA99 1TU

Contact details Part 3, p29 at the end of this booklet.

Social Services
Services that are available are listed in Part 1, p10.

Can I ask for a second opinion?
You are entitled to ask for a second opinion from another specialist at any stage in your treatment, although a second opinion is most commonly requested at diagnosis. You may ask your GP or your specialist to arrange for you to have a second opinion.

What happens after I have been given my diagnosis?
Your specialist will keep your GP informed about you. Your GP should be told quickly and in writing about your diagnosis and any proposed treatment. You can ask your specialist if you can have a copy of this letter. If you need further advice following your appointment with your specialist you should make an appointment with your GP.

You may need the help of social services in either the short or long term. You may wish to discuss this with your specialist, GP, or other health professional. If you are already under the care of social services it is a good idea to inform them of your diagnosis. They can then reassess the services they provide to you.
Hospital stay

How long will I have to wait to go into hospital?
As an inpatient (staying overnight in hospital) or day case patient (where no overnight stay is necessary) you should expect to wait no more than six months from the time the ‘decision to admit’ was made, to your stay in hospital. However, these are maximum waiting times and many people will be seen sooner.

What happens if I have any problems during my stay?
Hospitals will try to keep you informed about your treatment. As hospitals are busy places this is not always apparent, but you should remember that staff welcome your questions. Every Hospital Trust has a Patient Advice and Liaison Service (PALS). This service will be able to assist you with any major problems that may arise during your stay.

What happens when I leave hospital?
Hospital staff should work together to make sure that your care and support needs have been identified before you leave hospital. The nurses and doctors will talk to you about what will happen next and who you can contact in an emergency. A written discharge plan may be agreed with you. Your GP should be sent a copy of this plan by the hospital.

Questions to consider asking hospital staff before leaving hospital

If I need additional help at home where do I get this?
Will I need any rehabilitation?
Will I need to spend any further time in hospital?
For how long will I need to take my medication?
Are there any changes I need to make to my lifestyle?
Can I still drive?
Are there any local support groups I can contact?
Can I still work? If so when can I go back to work?
When will I see my specialist again?
Do I have to contact my GP or will my GP contact me?
People with long term neurological conditions living at home should have access to a comprehensive range of rehabilitation, advice and support services to meet continuing and changing needs, increase independence and autonomy, and help them to live as they wish.

You may have had contact with a social worker whilst in hospital. If you think you will need help from social services after you leave hospital; you can ask hospital staff to contact a social worker for you. If you need ongoing care at home community nurses can be arranged for you through your GP’s practice. You may be referred to community rehabilitation services.

Carers

What services are available to carers?
Carers look after family, partners, friends and disabled children who need support to live at home. The care they provide is unpaid.

If you are a relative or carer you can ask hospital staff if a named person is available to contact for help and advice. There may be an information pack giving details of local services and local carer support groups to support your role as a carer.

Carers of people with a neurological condition have the right to ask social services for a separate assessment of their needs. This includes young carers under 16 years. You do not have to be living with or related to the person to qualify for a carer’s assessment. If you care for a disabled child your needs will be considered as part of the assessment of the needs of your child and family. You can contact your social services department (address in the telephone book) for details.
If your situation changes (for example you are spending more time caring) then you may ask for your needs to be reassessed. It is a good idea to ensure that your GP is aware that you are the carer of a person with a neurological condition. Your health needs can then be fully assessed.

As a carer you may also qualify for state benefits, some of which are paid on top of any other income and benefits. The Carers (Equal Opportunities) Act 2004, which came into force in England and Wales in April 2005, gives local authorities powers to enlist the help of housing, health, education and other local authorities in providing support to carers.

**How can I take a break?**
Respite care provides a break from caring. There are many different sorts of respite care. It ranges from informal help from your family and friends to more formal respite care arranged through your GP or social services department. A temporary stay in a residential home for the cared for person and attendance at a day centre are examples of respite care. Provision of respite care may be discussed at your [carer’s assessment](#). You may also be able to arrange and pay for respite care privately.

**Ongoing management of your neurological condition**

**What happens in the longer term?**
Neurological conditions often lead to complex needs as they can affect many parts of the body. You may have more than one condition. You may also have a number of symptoms and these may worsen.

As many neurological conditions have long-term effects people need co-ordinated and patient-centred services.
To date these have not always been available but according to the NSF for long term conditions, it is to become a requirement. Part 1 of this booklet describes the services available to you. From time to time you could review whether you are benefiting from all the services you need. Do not assume that once you have made contact with particular services you will be automatically referred to all the services you need.

If your condition is progressing (that is getting worse) ask if there is any other help available to you when you next see a health professional. It is also useful to check with people who have given you advice in the past to see if you are entitled to any new services.

The white paper, Our health, our care, our say also states that people in the later stages of long term neurological conditions will receive palliative care services when required to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support.

**How often should my health and other needs be reviewed?**

Some neurological conditions are progressive (that is, they worsen) and others may remain static for a long period of time. Assessment and reassessment should be carried out at regular intervals. The Neurological Alliance recommends your GP or specialist should offer you an assessment at least once a year. The Government has agreed that everyone over 75 should normally have their medicines reviewed each year. If you are over 75 and take four or more medicines you should have a review every six months.

If you are experiencing chronic pain you could ask your GP to refer you to the nearest pain clinic.
Questions to consider asking yourself, your social worker, health professionals and your voluntary organisation

- Am I receiving all the benefits I am entitled to?
- Could I benefit from additional equipment?
- Are there any new treatments available I could benefit from?
- Would my carer benefit from additional help?
- Where is a welfare benefits advisor located?
- Where locally can I get help with equipment?
- Are there any clinical trials I could take part in?
- What help and organisations are there available locally for carers?
- How do I obtain further assistance to help me with my day to day living?
- Where can I get help with transport?
- Could I benefit from further rehabilitation?
- Am I receiving a newsletter from/in contact with the charity covering my condition?

Rehabilitation

Why is rehabilitation important?
The aim of rehabilitation is to help you regain your former skills where possible, and compensate for skills lost, to the best of your ability. When you are living with a neurological condition, undergoing rehabilitation can be a key factor in determining your quality of life. It is therefore important that you have access to appropriate equipment and to appropriate health and social care professionals, as necessary, and this is to become a requirement under the NSF for long term conditions. Such professionals may include speech and language therapists, occupational therapists, physiotherapists, neuropsychologists, clinical psychologists, rehabilitation physicians, orthotists and care managers.

You may benefit from rehabilitation in hospital or at home and at any stage of your condition. However where an acute or emergency episode has occurred, as for example with head injury, the greatest progress is often achieved over the following two years. In such cases a speedy referral to rehabilitation services is important. Rehabilitation usually ceases when it no longer produces sufficiently marked changes. However,
sometimes rehabilitation is needed to prevent things getting worse. Although it may not achieve measurable improvement, it is still worth while.

You should be reassessed regularly or as necessary, especially if your condition is changing. You may have to ask and keep asking either your GP or specialist for this to happen. This reassessment can be carried out by a rehabilitation physician, by your hospital or community rehabilitation team. The way this service is organised, and the procedures for referrals and assessments, varies throughout the country.

## Services for children

### What services are available if my child has a neurological condition?

The Children’s National Service Framework published in September 2004 sets standards for children’s health and social services, and how those services interact with education. The Children’s NSF focuses on early intervention, based on assessment of a child and the family’s needs, and improved access to services for all children according to their needs.

A number of neurological conditions are present from birth and others arise in childhood. Your child has the same rights to appropriate health, social and educational services as everyone else. The medical professionals treating your child are most likely to specialise in treating children. This is known as paediatric care. In some areas there are also specialist facilities for children, for example child development centres. These will assess your child’s development needs and help provide co-ordinated family support from health, social and education services.
Many neurological conditions will mean that a child will be covered by the legal definition of ‘disability’ entitling them to be considered for additional services. Your child is entitled to be assessed by social services at any age in order to establish what services can be provided for you and your child, for example, practical assistance at home or home adaptations. If it is agreed that services are needed, children’s social services will draw up a care plan. This summarises the services to be provided. You will be given a copy of this and it should be reviewed by children’s services every year.

**How does my child get extra educational help?**
If you think that your child has special educational needs (SEN) you should talk to their early years education setting/school about your concerns. You can ask your local education authority to carry out an SEN assessment which could lead to your child having a Statement of their SEN and the extra help needed to meet their needs. For disabled children, schools must make reasonable adjustments to allow the child to be included.

**What happens when my child reaches adulthood?**
At age 14 the local education authority will produce a Transition Plan for your child. This plan will review your child’s needs as they reach adulthood. It will include education and training needs, employment opportunities, accommodation requirements and leisure activities. Parents and the young person will be invited to the Transition Plan review meeting.

**How can parents ensure their child’s needs are met?**
You know your child best and your views, as well as those of your child, should be listened to and taken into account. You can contact the sources of advice and/or the association which covers your child’s condition (see section 3) for further help and information.
Concerns about care

**What can I do if I have concerns about my care?**

If you have concerns about any aspect of your care it is important that you tell someone as soon as possible so that it can be sorted out. Many problems arise through a breakdown in communication. The first step may be to speak to the person concerned. If you are unhappy with your medical care you may find it helpful to meet the doctor or health professional concerned. Consider asking a family member or friend to come with you to the appointment.

All **NHS Trust** hospitals, GP practices and community health services have a Patient Advice and Liaison Service (**PALS**) and a complaints procedure. PALS provides confidential advice and support to help you sort out any concerns about the care you are experiencing. It can provide details about how to complain. All social services departments also have a complaints procedure. If you contact social services they will explain how to make a complaint. If an organisation has a website it may contain information about how to complain.

**How do I gain access to my medical records?**

You have the right to see your medical records. You can ask your specialist, GP or therapist at the time of consultation to show you your records and if necessary explain your current care to you. If you want a copy of your records you must make a written request to the person who holds the records. You are likely to be charged for this service. Remember there may be records about you and your condition held in more than one place. Usually your GP’s records will be the most comprehensive. PALS can advise you how to obtain access to your medical records.
Part 3

Finding out more

Government

Charities – all neurological conditions

Charities – specific neurological conditions

Disability issues
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Government

**General**

www.direct.gov.uk is the gateway website for the UK government, providing access to information on the full range of public services.

**NHS services**

For questions about healthcare and NHS services you can either ring NHS Direct 24 hours a day on 0845 4647 or contact NHS Direct online at www.nhsdirect.nhs.uk

**Benefits**

For advice about benefits available to you and to carers contact:

- Or go to the ‘services and benefits’ section of the DWP website at www.dwp.gov.uk.
- the Benefit Enquiry Line for people with disabilities on 0800 882200 for advice.
- the voluntary organisation covering your condition listed on the following pages.
- Your social worker

Special educational needs (SEN)

For a guide for parents and carers on SEN and a copy of the SEN Code of Practice contact:

- The Department for Education and Skills
  - 0845 602 2260, extension 3
  - www.des.gov.uk

**Driver vehicle and licensing agency**

- DVLA Drivers’ Medical Unit
  - DVLA Longview Road
  - Swansea SA99 1TU
  - 0870 600 0301
  - www.dvla.gov.uk

**Employment**

www.jobcentreplus.gov.uk can help you find your local job centre and gives advice on helping you into work if you are disabled or have a health condition or are a carer.
Charities – all neurological conditions

Brain and Spine Foundation
Information and support about all neurological conditions.
Helpline 0808 808 1000
helpline@brainandspine.org.uk
www.brainandspine.org.uk

Brain and Spinal Injury Charity (BASIC)
Helpline 0870 750 0000
enquiries@basiccharity.org.uk
www.basiccharity.org.uk

Contact a Family
The charity holds an index of specific conditions and rare disorders.
Helpline 0808 808 3555
info@cafamily.org.uk
www.cafamily.org.uk

NeuroSupport
(formerly Mersey Neurological Trust)
Provide non-medical information and support to people with neurological conditions.
0151 298 2999
info@neurosupport.org.uk
www.neurosupport.org.uk

Sue Ryder Care
Provides neurological care centres
020 7400 0440
info@suerydercare.org
www.suerydercare.org
Charities – 
specific neurological conditions

If your neurological condition is not listed, please contact one of the charities on the previous page which deal with all neurological conditions. They will be able to suggest the charity most suited to your needs.

**Acoustic neuroma**
British Acoustic Neuroma Association
Freephone 0800 652 3143
admin@bana-uk.com
www.bana-uk.com

**Ataxia**
Ataxia UK
Helpline 0845 644 0606
helpline@ataxia.org.uk
www.ataxia.org.uk

**Ataxia-telangiectasia**
Ataxia-Telangiectasia Society
01582 760733
atcharity@aol.com
www.atsociety.org.uk

**Brain tumour**
Brain Tumour UK
0845 4500 386
enquiries@braintumouruk.org.uk
www.braintumouruk.org.uk

Samantha Dickson Brain Tumour Trust
0845 130 9733
patientinfo@sdrt.co.uk
www.sdrt.co.uk

**BSE**
Human BSE Foundation
0191 389 4157
info@hbsef.org
www.hbsef.org

**Cerebral palsy**
Scope
Helpline 0808 800 3333
cphelpline@scope.org.uk
www.scope.org.uk

**Charcot-Marie-Tooth disease**
CMT
0870 7744 314
secretary@cmt.org.uk
www.cmt.org.uk

**Dementia**
Alzheimer’s Society
Helpline 0845 300 0336
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

For Dementia
020 7874 7210
info@fordementia.org.uk
www.fordementia.org.uk

**Dyspraxia**
DANDA (Developmental Adult Neuro Diversity Association)
020 7435 7891
mary@pmcolley.freeserve.co.uk
www.danda.org.uk
**Dystonia**
The Dystonia Society
Helpline 0845 458 6322
info@dystonia.org.uk
www.dystonia.org.uk
ADDER (Action for Dystonia, Diagnosis, Education and Research)
0191 413 9500
butler.adder1@btinternet.com
www.dystonia.co.uk

**Encephalitis**
Encephalitis Society
01653 692588
support@encephalitis.info
www.encephalitis.info

**Epilepsy**
Epilepsy Action
Helpline 0808 800 5050
helpline@epilepsy.org.uk
www.epilepsy.org.uk
The National Society for Epilepsy
Helpline 01494 601400
www.epilepsynse.org.uk
The National Centre for Young People with Epilepsy (NCYPE)
01342 832 243
info@ncype.org.uk
www.ncype.org.uk

**Guillain Barré Syndrome**
Guillain Barré Syndrome Support Group
Helpline 0800 374803
admin@gbs.org.uk
www.gbs.org.uk

**Head and Brain Injury**
Headway
Helpline 0808 800 2244
helpline@headway.org.uk
www.headway.org.uk
Child Brain Injury Trust
Helpline 0845 601 4939
helpline@cbituk.org
www.cbituk.org
Rehab UK
020 8579 9671
ninahillier@rehabuk.org
www.rehabuk.org

**Headache and Migraine**
Migraine Trust
020 7436 1336
info@migrainetrust.org
www.migrainetrust.org
Migraine Action Association
0870 050 5898
www.migraine.org.uk

**Hemiplegia**
Hemihelp
0845 123 2372
support@hemihelp.org.uk
www.hemihelp.org.uk

**Huntington’s disease**
Huntington’s Disease Association
0151 298 3298
info@hda.org.uk
www.hda.org.uk
Hydrocephalus
Association for Spina Bifida and Hydrocephalus (ASBAH)
01733 555988
info@asbah.org
www.asbah.org

Meningitis
Meningitis Trust
0800 028 1828
helpline@meningitis-trust.org
www.meningitis-trust.org

Myalgic encephalomyelitis (ME)
ME Association
Helpline 0870 444 1836
meconnect@meassociation.org.uk
www.meassociation.org.uk

The National ME Centre
01708 378050
nmecent@aol.com
www.nmec.org.uk

Motor neurone disease
Motor Neurone Disease (MND) Association
Helpline 08457 626262
helpline@mnassociation.org
www.mndassociation.org

Multiple sclerosis
Multiple Sclerosis Society
Helpline 0808 800 8000
www.mssociety.org.uk

Multiple Sclerosis Trust
01462 476700
info@mstrust.org.uk
www.mstrust.org.uk

Multiple system atrophy
The Sarah Matheson Trust for Multiple System Atrophy
020 7886 1520
www.msaweb.co.uk

Muscular dystrophy
Muscular Dystrophy Campaign
020 7720 8055
info@muscular-dystrophy.org
www.muscular-dystrophy.org

Myasthenia gravis
Myasthenia Gravis Association
Helpline 0800 919922
mg@mgauk.org.uk
www.mgauk.org

Narcolepsy
Narcolepsy Association UK (UKAN)
0845 450 0394
info@narcolepsy.org.uk
www.narcolepsy.org.uk

Neurofibromatosis
Neurofibromatosis Association
020 8439 1234
info@nfauk.org
www.nfauk.org

Parkinson’s disease
Parkinson’s Disease Society
Helpline 0808 800 0303
enquiries@parkinsons.org.uk
www.parkinsons.org.uk
Polio
British Polio Fellowship
Freephone 0800 018 0586
info@britishpolio.org.uk
www.britishpolio.org.uk

Lincolnshire Post-Polio Network
01522 888601
info@lincolnshirepostpolio.org.uk
www.lincolnshirepostpolio.org.uk

Progressive supranuclear palsy
The Progressive Supranuclear Palsy (PSP Europe) Association
01327 322410
psp@pspeur.org
www.pspeur.org

Rett syndrome
Rett Syndrome Association UK
0870 770 3266
info@rettsyndrome.org.uk
www.rettsyndrome.org.uk

Spina bifida
Association for Spina Bifida and Hydrocephalus (ASBAH)
01733 555988
info@asbah.org
www.asbah.org

Spinal injuries
Spinal Injuries Association
Helpline 0800 980 0501
sia@spinal.co.uk
www.spinal.co.uk

Syringomyelia
The Ann Conroy Trust
01788 537676
www.theannconroytrust.org.uk

Stroke
The Stroke Association
Helpline 0845 303 3100
info@stroke.org.uk
www.stroke.org.uk

Different Strokes
(for younger stroke survivors)
Helpline 0845 130 7172
info@differentstrokes.co.uk
www.differentstrokes.co.uk

Tourette syndrome
Tourettes Action
Helpline 0845 458 1252
help@tourettes-action.org.uk
www.tourettes-action.org.uk

Transverse Myelitis
Transverse Myelitis Society
020 8568 0350
lewgray@blueyonder.co.uk
www.myelitis.org.uk

Tremor
National Tremor Foundation
Freephone 0800 328 8046
tremorfoundation@aol.com
www.tremor.org.uk

Tuberous sclerosis
Tuberous Sclerosis Association
0121 445 6970
support@tuberous-sclerosis.org
www.tuberous-sclerosis.org
Disability issues

DIAL UK
01302 310123
www.dialuk.info

Disability Rights Commission
Helpline 08457 622 633
www.drc-gb.org

Disabled Living Foundation
Helpline 0845 130 9177
advice@dlf.org.uk
www.dlf.org.uk

RADAR (Royal Association for Disability and Rehabilitation)
020 7250 3222
radar@radar.org.uk
www.radar.org.uk

Education

Independent Panel for Special Education Advice (IPSEA)
0800 0184016
ipsea.info@intamail.com
www.ipsea.org.uk

National Parent Partnership
020 7843 6058
www.parentpartnership.org.uk

Transition Information Network (TIN)
020 7843 6006
tin@ncb.org.uk
www.transitioninfonetwork.org.uk

Pain

Pain Concern
01620 822572
info@painconcern.org.uk
www.painconcern.org.uk

Speech, language and communication difficulties

Speakability
Helpline 0808 808 9572
speakability@speakablity.org.uk
www.speakability.org.uk

Connect
020 7367 0840
info@ukconnect.org
www.ukconnect.org

Carers

Carers UK
Carersline: 0808 808 7777
info@carersuk.org
www.carersuk.org

Crossroads Association
0845 450 0350
www.crossroads.org.uk

Regional alliances

There are also a number of regional alliances throughout England as well as neurological alliances in Scotland and Wales. For contact details please contact the Neurological Alliance.
Glossary

These are some of the terms and people you may come across when using neurological services.

**Angiogram**
This is an x-ray used to make pictures of blood vessels. It is a common test for neurological conditions.

**Care managers**
Social workers who are responsible for the overall management of a person’s social care package.

**Carer’s assessment**
The assessment undertaken by social services to assess the needs of a person caring for a person.

**Community nurses**
Nurses who offer a range of nursing services within your own home. They may include district nurses, health visitors, community paediatric nurses, palliative care and other specialist nurses. They can be contacted through your GP.

**Community rehabilitation services**
Rehabilitation services that are based in the community rather than a hospital.

**Congenital**
A description of a condition that is present from birth.

**CT Scan**
This stands for computerised tomography. It is a special x-ray that takes pictures of your head, brain and spine. It is a common test for neurological conditions.

**Diagnosis**
The identification of an illness taking into account your symptoms, medical history and the results of any tests.

**Dieticians**
Health professionals who provide advice on specialist diets, weight loss and gain, and the nutrition requirements of adults and children. They promote good health by helping you to make positive changes in food choices. Referral can be through your GP, specialist or through your social services department.

**Disability employment advisers**
Civil servants who provide specialist advice and support on all aspects of disability and employment.

**Geneticists**
Doctors who can explain the genetic cause of your condition and advise you about the hereditary implications.

**MRI Scan**
This stands for Magnetic Resonance Imaging. It is a scanning procedure used to produce very detailed pictures of your body and brain. It is a common test for neurological conditions.

**Neurologists**
Doctors who specialise in conditions of the brain, spinal cord, peripheral nerves and muscles.
Neurophysiologists
Doctors who specialise in testing the electrical function of the nervous system (electroencephalograms [EEGs] and tests on nerves and muscles).

Neurophysiotherapists
Physiotherapists who specialise in working with people with neurological conditions.

Neuropsychologists and clinical psychologists
Psychologists who assess your mental skills e.g. memory and concentration, using specially designed tests. They advise on management, rehabilitation and retraining both in hospital and the community. They can also provide advice and counselling on dealing with emotional problems caused by neurological conditions.

Neurosurgeons
Doctors who specialise in the surgical treatment of the brain, spinal cord and peripheral nerves.

NHS Trust
An organisation responsible for hospital and/or community health services.

Occupational therapists
Health professionals who help with practical aspects of looking after yourself, and with work and leisure activities. They will often assess your home environment to make it as manageable as possible. They may be based with social services, in which case they will be responsible for organising adaptive equipment and home adaptations through social services, or they may be hospital based. Referral can be through your GP, specialist or through your local social services department.

Ophthalmologists
Doctors who specialise in eye conditions.

Orthosis
This is a device fitted to a part of the body in order to improve its function or reduce pain.

Orthotists
Health professionals who assess, measure, design, fit, supply and review of orthoses.

Out of area treatments
Treatment undertaken out of your local primary care trust area.

Paediatric care
The medical care of children.

Paediatrician
A doctor who specialises in the medical care of children.

Paediatric neurologist
A doctor who specialises in childhood neurological conditions.

PALS
This stands for Patient Advice and Liaison Service. All trusts running hospitals, GP practices and community health services have a PALS. The service is available to
all patients, their families and carers to help resolve problems and to listen to concerns about the treatment, care and support that they are receiving.

**Physiotherapists**
Health professionals who advise on exercises that can help you maintain, recover and improve your ability to use your muscles and joints so that they are as mobile as possible. They advise on lifting, posture and breathing exercises. They also advise carers on safe ways of lifting and moving someone with mobility problems. Your GP or hospital doctor will be able to refer you to see a community physiotherapist in your home, in the hospital physiotherapy department or in your child’s school.

**Primary Care Trusts**
The NHS organisation responsible for your general practitioner (GP) and other staff, such as community nurses, operating from your GP’s practice or health centre.

**Prosthesis**
A specially manufactured replacement for a part of the body

**Prosthetists**
Health professionals who are responsible for the assessing, measuring, design, fit, supply and review of prostheses.

**Rehabilitation physicians**
Doctors specialising in maximising the potential of someone with a disabling condition. They work with a multidisciplinary team, having links and access to various therapists, social services and specialist equipment.

**Social workers**
Professionals who are skilled in helping families receive the practical help they need. They may be involved in assessing your needs. They also plan and co-ordinate services, offer advice on services and benefits and can offer support if you need to talk things through.

**Specialists**
Hospital-based doctors who specialise in a specific group of conditions.

**Specialist nurses**
These are neurological nurses and also condition-specific nurses eg. multiple sclerosis specialist nurse, Parkinson’s disease nurse, epilepsy nurse specialist. They are usually hospital-based and often play a key role in the co-ordination of care.

**Speech and language therapists**
Therapists who provide practical help for people who have developed difficulties with either communication or swallowing. Referral can be through your GP, specialist or through your local social services department.
This booklet was produced following extensive consultation with people with neurological conditions, their carers, the charities that represent them and the professionals who work with them.