

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 tests I need to undertake before my appointment?

Are there any services I would benefit from whilst I am waiting for a diagnosis?

Is there any written material available?

‘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

→ Part 3, p30, charities list

You do not need to have any diagnosis to receive help and advice from charities. You may contact them at any time.

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?

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

What is the likelihood of success of the treatment?

When will I know if the treatment has worked?

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 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?

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?

? ask your specialist

A good way of finding out more is to put questions to your specialist. In the panel above there are some suggestions. It may be useful for you to talk through your questions with a friend or relative before your appointment. You could write your questions down and take them with you to your appointment.

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.

i for more information

The charity 'Contact a Family' holds an index of rare conditions and can put you in touch with an organisation covering your condition.

☎ 0808 808 3555

➔ Contact details are listed in Part 3, p30, in this booklet.

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.

However, sometimes it may be necessary for additional advice to be sought from a specialist who works outside your area. This is known as ‘out of area treatment.’ You will not have to pay for this, although you will have to pay your own travel expenses to see that specialist. If you are in receipt of state benefits you may reclaim those travel expenses. There is a form available from either your referring doctor or your hospital.

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.

i	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.

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

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.

? concerns about care

→ See Part 3, p29, of this booklet.

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?

Who will have overall responsibility for my care once I leave hospital?

If I have any concerns about my condition who do I contact?

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

	sources of advice
	See information on how to find out more about benefits in Part 3, p29, of this booklet.
	There are a number of national charities for carers and some are listed in Part 3 of this booklet.
	Carers UK: 0808 808 7777
	www.carersuk.org
	Carers UK provides information about where to find out about different types of respite care.
	Part 3, p30, charities list
	Some neurological charities also either provide respite care or will be able to help you find good quality respite care.

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

'Being asked by a neurologist if there was anything they could do to help me cope or make me comfortable – including me in decisions concerning the management of my condition had such a positive impact on my self-esteem.'

Person with Charcot-Marie-Tooth disease

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?

Where is a welfare benefits advisor located?

How do I obtain further assistance to help me with my day to day living?

Could I benefit from additional equipment?

Where locally can I get help with equipment?

Where can I get help with transport?

Where can I find help locally to return to work?

Are there any new treatments available I could benefit from?

Are there any clinical trials I could take part in?

Could I benefit from further rehabilitation?

Would my carer benefit from additional help?

What help and organisations are there available locally for carers?

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,

i	sources of advice
Your GP or specialist can help you with a referral.	

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

i	sources of advice
The Charity 'Contact a Family' has a guide for parents of children with additional needs which includes information on assessments by children's social services. Briefings on SEN and on Transition are also provided.	
➔	Contact a Family full contact details listed, Part 3, p30.
The Department for Education and Skills produces guidelines on how to seek a special educational needs assessment.	
☎	0845 602 2260 ext 3
➔	DES full contact details listed, Part 3, p29, at the end of this booklet.

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.

i	sources of advice
	The Parent Partnership service and IPSEA (Independent Panel for Special Education Advice) can also help parents with educational issues
→	Parent Partnership and IPSEA contact details are listed, Part 3, p35.
	The Transition Information Network (TIN) can help with information on all aspects of transition
→	TIN contact details are listed, Part 3, p35.

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

i	sources of advice
	NHS Direct 0845 4647
	In addition to PALS you can phone NHS Direct for assistance on matters relating to Trusts and GPs.
	NHS contact details are listed in Part 3, p29

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.