

Part 3

Finding out more — Glossary

Government

Charities – all
neurological conditions

Charities – specific
neurological conditions

Disability issues

Pain

Speech, language
and communication
difficulties

Carers

Regional alliances


Finding out more

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:

 your local Department for Work and Pensions. Look in your local phone book under 'Department for Work and Pensions', 'DWP' or 'Benefits Agency'.

 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@sdrct.co.uk
www.sdrct.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 699599

 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

 020 7022 1950

 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

 nmeacent@aol.com
www.nmec.org.uk

Motor neurone disease


Motor Neurone Disease (MND) Association

 Helpline 08457 626262

 helpline@mndassociation.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 860299
 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

Tourette Syndrome (UK) Association

 Helpline 0845 458 1252
 enquiries@tsa.org.uk
www.tsa.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.transitioninfonynetwork.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@speakability.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.



© Neurological Alliance 2006
ISBN 1 901893 34 0

Neurological Alliance,
Stroke House, 240 City Road,
London EC1V 2PR
020 7566 1540
admin@neural.org.uk
www.neural.org.uk

Company limited by guarantee. Registered in England 2939840.
Registered Charity 1039034