



the brain injury association



Parkinson's  
Disease Society



Huntington's  
Disease  
Association



Muscular  
Dystrophy  
Campaign

# SWANO

The South West Alliance of  
Neurological Organisations

A summary of information about  
neurological conditions and neurological  
voluntary organisations in the South West

[www.swano.org](http://www.swano.org)



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## **Introduction**

This directory has been compiled to provide basic information about nine of the most common neurological conditions in your area, to give a brief overview of the needs of this group of people and information about the work of nine neurological charities working in the NHS South West area.

Across the NHS South West, there are estimated to be nearly one million people living with some type of neurological condition. For these nine conditions alone, there will be in excess of 75,000 people living in the South-West (appendix 1).

The NSF for Long-term Conditions (March 2005) aims to 'transform the way health and social care services support people with long-term neurological conditions to live as independently as possible'.

Whilst it is understood that commissioners have a number of competing priorities, and that the National Service Framework for Long-Term (neurological) conditions is a ten-year plan for improvements, there are clear advantages for statutory organisations, users and carers in improving services to meet the targets contained within the document.

### **Services needed by people with a neurological condition**

A common factor across all neurological conditions is that people affected will require monitoring, care and support from a number of different health and social care professionals. Nearly all will need contact with members of the 'core' team<sup>1</sup>, although each neurological condition may have need for more specific services in addition. Where this is the case, this is made clear in the relevant section of this directory.

### **The South-West Alliance of Neurological Organisations (SWANO)**

Regional representatives are working together as the South-West Alliance of Neurological Organisations. One of SWANO's main aims is "to work together on common neurological issues and to collectively influence Health and Social Care organisations at a strategic level across the South West, on the basis that the collective might of the network is likely to have more impact than individual attempts at influencing."

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<sup>1</sup> The 'core' multidisciplinary team is assumed to consist of consultant neurologists, occupational therapists, physiotherapists, dietitians, speech and language therapists, psychologists, care managers.

**What SWANO can do for you**

1. Give you information about the specific neurological conditions which will assist you in commissioning the most appropriate services for people with neurological conditions
2. Act as a specialist resource
3. Put you in touch with users of services and carers when you need to seek their views
4. Share good practice with you from other health and social care organisations
5. Help develop or refine care pathways
6. Work in partnership with you for some aspects of care.

In particular, we can help in developing your services to meet the NSF targets relating to:

- A person-centred service
- Early recognition, prompt diagnosis and treatment
- Emergency and acute management
- Early and specialist rehabilitation
- Community rehabilitation and support
- Vocational rehabilitation
- Providing equipment and accommodation
- Personal care and support
- Palliative care
- Supporting families and carers
- Care during hospital admission or in other care settings

## Multiple Sclerosis (MS)

### The condition

- Multiple Sclerosis (MS) is the most common disabling neurological condition affecting young adults
- Women are almost twice as likely as men to develop MS
- Most people are diagnosed with MS between the ages of 20 to 40
- For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

### Incidence and prevalence

- Around 100,000 people in the UK have MS (figures were revised upwards significantly in 2009 following research commissioned by the MS Society).
- Based on the revised 2009 figures, it is likely that there are in excess of seven thousand people living with MS in the region.

### The impact on health and social care services

Over the course of their disease, people with MS are likely to require input from a large number of all the core health and social care professionals\*, but also

Specialist nurses

Continence advisory and management services

Pain management services

Chiropody and podiatry

Ophthalmology services

Clinical psychologists

Palliative care services

Paid carers

People affected by MS may need a range of equipment to maintain their independence, such as specialised wheelchairs and other mobility aids, bathing equipment, environmental controls, communication aids and others.

### The MS Society

*The MS Society funds* MS research, runs respite care centres, provides financial assistance, education and training on MS. It produces a wide range of publications on MS and runs a free phone specialist helpline (0808 800 8000)

The Society is committed to bringing high standards of quality health and social care within reach of everyone affected by MS and to encouraging and supporting medical and applied research into its cause and control.

The MS Society has one salaried service development officer working in the NHS South West area and one salaried local support development officer working mainly with branches. They are supported by regional managers, covering wider areas and with additional responsibilities

There are over twenty branches in the South West providing information and support for people affected by MS and their families and carers.

Details of local contacts can be found on the MS Society's website at [www.mssociety.org.uk](http://www.mssociety.org.uk).

## Motor Neurone Disease (MND)

### The condition

- MND is a rapidly progressive, fatal disease.
- The cause of MND is unknown and there is no known cure.
- It is most common after the age of 50; the ratio of men:women affected is 3:2
- 50% of all people die within 14 months of diagnosis
- It is characterised by progressive muscle weakness which may leave a person unable to walk, use their arms, or talk, whilst their intellect frequently remains intact.

### Incidence and prevalence

- The incidence of MND is approximately two per 100,000, which suggests that there will be 101 new cases of MND diagnosed each year in the South West.
- The prevalence of MND is approximately seven per 100,000, which would result in 353 currently living with MND in the South West.

### The impact on health and social care services

Over the course of their disease, people with MND are likely to require input not only from the core team of health and social care professionals\*, but also from:

- Gastro-enterology/endoscopy team
- Respiratory team
- Specialist palliative care services
- Paid carers – for direct care and also for carer respite

A large number of pieces of specialist equipment is likely to be required (eg. specialised wheelchairs, non-invasive ventilators, environmental controls, communication aids).

In the latter stages, funding is frequently required from Continuing Health Care budgets.

### The MND Association

The MND Association funds and provides research to bring about an end to MND. In the meantime, it aims to do all it can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and die with dignity. The Association also does all that it can to support the families and carers of people with MND.

The MND Association has three salaried [Regional Care Development Advisers](#) working in the NHS South West area plus a Volunteering Development Co-ordinator and 41 Association Visitors, who are trained volunteers. There are also thirteen Association Branches and Groups in the South West that are involved in raising awareness, influencing, fundraising and providing information and support for people with MND and their families and carers.

### Other

Unlike many other parts of the country, there is no MND Care Centre within the South West. It is a priority of the Association to develop two MND Care Centres in the region.

They provide:

- a specialist resource for people living with MND
- access to a multidisciplinary team
- strong links with the local community services and the MND Association sharing of good practice through education and Special Interest Groups
- a focus for clinical research and a centre for clinical drug trials.

Details of all local contacts can be found on the Association's website at [www.mndassociation.org](http://www.mndassociation.org)

## **Progressive Supra-Nuclear Palsy (PSP)**

### **The condition**

- PSP is a progressive neurological and inevitably fatal disease
- There is currently no known cure or viable medication
- It generally affects people over the age of 60 but has been known to occur at a younger age
- Lifespan after onset of symptoms is approx 5-7yrs but early diagnosis is rare and many patients die within 2-3yrs after correct diagnosis
- Symptoms are varied and in early stages tend to generate falls (usually backwards), progressing to difficulties with speech and swallowing, vision, continence and mobility whilst the intellect generally remains intact.

### **Prevalence**

- According to recent research the prevalence is thought to be 6 per 100,000 which would relate to approx 303 people living with PSP in the South West
- Leading neurologists believe this number to be seriously understated as many are mis-diagnosed or undiagnosed.

### **The impact on health and social care services**

Any person living with this disease - whether diagnosed or not - will need to have call on many and varied members of the health and social care professions including:

- Neurology consultant, specialist nurse,
- Occupational therapist
- Physiotherapist
- Speech and Language therapist
- Dietician
- Palliative Care services
- Paid carers – for direct care or respite
- Social service provision of mobility equipment and home-safety equipment

In latter stages of the disease there will probably be a requirement for funding from the Continuing Care budget which needs to be better accessed.

### **The PSP Association**

This is an advocacy organisation promoting research worldwide into PSP and providing information and support to afflicted families. Local support groups are organised wherever there are enough patients. There are currently 16 such groups across the UK – with more in the process of being organised. It is hoped there will be at least four in the southwest where there are only two at present.

The **PSP Association** is a small charity but has recently funded 6 Regional Development Officers across the country – 1 of which has responsibility for the Southwest and is committed to raising awareness of this disease amongst the Health and Caring professions to facilitate earlier diagnosis and relevant treatment of the condition.

It has also funded 3 specialist nurses across the UK who are available for advice and support on dedicated helplines and also provide in-depth training sessions when required.

Further information is available on the Associations website – [www.pspeur.org](http://www.pspeur.org) or by telephoning 01327 322410 or e-mail [psp@pspeur.org](mailto:psp@pspeur.org)

## Cerebral Palsy (CP)

### The condition

Cerebral Palsy is a condition that affects movement, posture and co-ordination caused by the immature brain receiving an injury or not developing properly. Causes can be multiple and complex and sometimes there is no obvious single reason as to the cause of cp. Possible causes include:

- The mother or the baby having an infection in early pregnancy
- Difficult or premature birth
- Cerebral (brain) bleed or abnormal development of baby's brain
- A genetic link (however, this is quite rare)

There are three main types of cp, although most people will have a combination of the different types.

- Spastic cerebral palsy – most common form. The muscles are stiff and have limited range of movements.
- Athetoid or Dyskinetic cerebral palsy – involuntary movements as muscle tone changes from floppy to tense. May also experience difficulty with hearing and speech.
- Ataxic cerebral palsy – balance is difficult with unco-ordinated movements affecting the whole body. May have shaky hands and irregular speech.

In some people, cerebral palsy is barely noticeable. Others will be more severely affected. No two people with cerebral palsy are the same.

### Incidence and Prevalence

The widely accepted figure for people with cerebral palsy (cp) in the general population is one in four hundred (1:400) or 2 - 2.5 per thousand live births. This equates to approximately 113,510 people with cp in the UK, based on approximately 1800 children being born with cp each year and a UK projected population (in the 2001 census) of 61,269000. It is generally accepted that cp is the most prevalent physical impairment amongst children. Extreme caution has to be applied to any data on cerebral palsy.

### Impact on Health & Social Care Services

Cerebral Palsy cannot be 'cured' but early support and therapeutic intervention can help with development and the effects of cp upon the muscles and motor control. Most people with cp will require intervention from a number of professionals throughout life including:

- Social Services
- GP
- Paediatricians and specialist consultants e.g. Orthopaedic Surgeons, Neurologists, Physiotherapists, Occupational Therapy and Speech and Language Therapists
- Respite and Domiciliary Care
- Specialist Carers

### Scope

Scope's services include creating early years, education, independent living and employment opportunities for disabled people. To find out more about Scope's work, visit [www.scope.org.uk](http://www.scope.org.uk). Scope's mission is to drive the change to make society the first where disabled people achieve equality.

Scope Response is the first point of contact for information, support and advice on all aspects of cerebral palsy and disability issues. Tel: 0808 800 3333

Email: [response@scope.org.uk](mailto:response@scope.org.uk) Text: Send a text message to SCOPE followed by your message to 80039

## **Parkinson's Disease (PD)**

### **The Condition**

- PD is a progressive neurological disorder affecting learned voluntary movements such as walking, talking, writing and swallowing – caused by a loss of a chemical messenger (dopamine) in the brain.
- There are three main symptoms: tremor, rigidity and slowness of movement, but not everyone will experience all three.
- The cause is as yet unknown and there is no known cure.
- PD affects slightly more men than women

### **Incidence and prevalence**

- PD affects 1 in 500 of the general population
- PD affects 1 in 100 of those over the age of 65 years
- PD affects 1 in 50 of those over the age of 80 years
- 1 in 7 are diagnosed before the age of 50 years
- 1 in 20 are diagnosed before the age of 40 years

### **The impact on health and social care services**

In addition to the core team of health and social care professionals\*, as the illness progresses people living with PD are likely to require support from:

Geriatrician and Physician Teams

PD Specialist Nurses and Support Nurses

Respite care services

Domiciliary care services

Palliative care services

Care Manager and Care Packages

### **The Parkinson's Disease Society**

The aims of the Parkinson's Disease Society are to provide information, support and advice to people living with PD and fund research into the condition.

There are 42 Branches and Support Groups in the South-west offering mutual support and a network of 8 Community Support Workers who provide a "signposting" and information service. The South-west Staff Team is managed by a Regional Manager and includes Branch and Volunteers Support Officers, Education and Training Officer, Service Development Officer and Information and Support Manager.

Details of local Regional contacts, Branch and Support Groups etc can be found on our website [www.parkinsons.org.uk](http://www.parkinsons.org.uk) or by contacting our free & confidential National PDS Helpline telephone: 0808-800-0303

## Brain Injury

### The condition

- Head injury is the foremost cause of death and disability in young people<sup>2</sup>
- An Acquired Brain Injury is an injury caused to the brain since birth. There are many possible causes, including a fall, assaults, a road accident, tumour and stroke.
- Every year approximately two-hundred thousand people sustain a brain injury of some sort. The effects of the injuries are usually for life, therefore the number of people living with brain injury will rise year on year.
- The effects of brain injury are often devastating and can include physical disability, memory loss, speech problems and rapid mood changes but has no impact on life expectancy. For many, it is parents and relatives who will become the main carers

### Prevalence

- Men are three times more likely to have a brain injury than women and men aged between 15-29 are FIVE times more likely to suffer brain injury.
- Across the UK, around 135,000 people are admitted to hospital each year as a consequence of brain injury – Tennant 2005

### The impact on social care services

Over the course of their lives, people with an ABI are likely to require input from many health and social care professionals in addition to the 'core' team, including:

- Neuropsychiatrists
- Neuropsychologists
- Consultant radiographers (not directly, but indirectly to interpret results of scans)
- Psychotherapist
- Cognitive Behavioural Therapist
- Specialist Nurses

### Headway

Headway - the UK's leading brain injury charity - provides support, services and information to brain injury survivors, their families and carers as well as professionals (health, legal etc).

Headway UK is an umbrella organisation (with office bases in Nottingham, London and Scotland) with a network of affiliated Headway Groups that run Headway Centres with employed staff and Headway Branches that are run on a voluntary basis throughout the UK. The organisation offers information and support to people with brain injuries, their families and carers by operating a National Helpline, publishing numerous publications and fact sheets and a quarterly magazine. Further details of services and the network of Groups and Branches can be obtained from our website: [www.headway.org.uk](http://www.headway.org.uk)

Headway currently provides training courses in understanding brain injury, cognitive rehabilitation and sex and sexuality following brain injury.

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<sup>2</sup> House of Commons: *Head Injury Rehabilitation, Health Committee Third Report*. London: The Stationery Office: 2001

## Huntington's Disease (HD)

### The Condition

- HD is a progressive, hereditary neurological disorder which used to be known as Huntington's Chorea.
- Symptoms are wide ranging and usually begin in middle adulthood, but can occur at any age.
- HD is caused by a faulty gene on chromosome 4, which leads to damage of nerve cells in specific areas of the brain.
- Each person whose parent has HD is born with a 50:50 chance of inheriting the faulty gene. Anyone who inherits the faulty gene will, at some stage, develop the disease.
- The course of the disease is unpredictable and involves a triad of movement, thinking and emotional symptoms, which vary even within the same family.
- Early symptoms might include involuntary movements, clumsiness, lack of concentration, short term memory lapses, depression, mood change, irritability and aggressive outbursts.
- Symptoms gradually deteriorate over approximately 10 – 20 years. In the later stages there tends to be a more global dementia, a continuation of psychological symptoms, an inability to communicate verbally, impaired swallow, complete physical dependence.
- There is no known cure for HD and effective treatment of symptoms remains in the experimental stage.

### Incidence and Prevalence

- 1 in 20,000 of the population are symptomatic at any one time in the UK.
- 3 times this number are pre-symptomatic.
- Many more than this are living with being at risk, but have not been tested.

### The impact on health and social care services

In addition to the 'core' team, people living with HD may require support from:

Genetic Services

Mental Health Services

Domiciliary and Palliative Care Services

Respite Services

Specialist equipment is likely to be required (e.g. specialised beds, chairs and wheelchairs, communication aids).

### The Huntington's Disease Association

This organisation exists to support people affected by Huntington's Disease. It has a central information service, a regional care advisory service, local branches and groups throughout the country and a research programme. It offers a helpline service, a twice-yearly newsletter, publications and information, a welfare grant fund and a respite and residential care fund. Details of all services can be found on the website: [www.hda.org.uk](http://www.hda.org.uk) or by phoning the head office on 0207 022 1950.

## Stroke

### The Condition

- Stroke is the largest cause of disability
- Stroke affects people of all ages
- Stroke is a 'brain attack' that occurs 'in a stroke' giving a sudden onset of symptoms
- About one third of people who have a stroke will die, one third will make a recovery and one third will be left with a disability.

### Incidence and Prevalence

- Around 150,000 in the UK have a stroke annually. 85,000 will be a first stroke, 10,000 will be under retirement age, 1,000 under 30 and 1,000 will be children.
- About 10,000 people in the south west will have a stroke or TIA (or mini stroke) each year - ASSET for Commissioners DOH – which means approx one every hour.

### The Impact on health and social care services

Organised stroke care is shown to be beneficial to outcome. Therefore stroke survivors and their carers are likely to require input from a large number of core health and social care professionals during their rehabilitation and the long term. Those involved include:

- Stroke clinicians
- Specialist stroke nurses/consultant nurses
- Clinical Psychologists
- Paid Carers
- Speech and language therapists, Dieticians
- Occupational therapists, Physiotherapists
- Communication Support Groups

People who have survived a stroke may require a range of equipment to maintain their independence such wheelchairs and other mobility aids, bathing equipment, communication aids and others.

### The Stroke Association

We want a world where there are fewer strokes and all those touched by stroke get the help they need. Our mission is to prevent strokes, and reduce their effect through providing services, campaigning, education and research. It funds research, provides commissioned services, welfare grants, education and training on stroke.

- It produces a wide range of publications on all aspects of stroke and its effects.
- It runs a helpline on 0845 3033100, and a website at [www.stroke.org.uk](http://www.stroke.org.uk).
- It campaigns to raise awareness of stroke at all levels of society.

The regional office for the south west is in Exeter. There is a regional manager, an assistant regional manager and information officer. Currently there are 12 Communications Support services and 8 Family and Carer Support Services.

## Muscular Dystrophy

### The conditions

- Muscular Dystrophies and related conditions are genetic conditions affecting the muscles. Some Spinal Muscular Atrophies and Hereditary Motor and Sensory Neuropathies affect the nerves and in turn affect muscle strength.
- There are more than twenty types of Muscular Dystrophy and they cause progressive muscle weakness because muscle cells break down and are gradually lost.
- Duchenne Muscular Dystrophy is the most common in childhood usually affecting boys, and is usually diagnosed between 1-5 years of age.
- Myotonic dystrophy is the most represented in the adult population.
- For some people their Muscular Dystrophy is seriously disabling and for others may be life limiting. Some people may be more mildly affected.

### Incidence

- The prevalence of these conditions is 50 per 100,000.
- Of the 30,000 people in the UK who have muscular dystrophy or a related condition, 4000 are children.
- Duchenne Muscular Dystrophy affects 1 in 3,500 live male births.

### The impact on health and social care services

In addition to the 'core' team, people with a Muscular Dystrophy may need input from:

- Specialist neurologists, adult and paediatric
- Spinal surgeons
- Pain management
- Specialist advisors/Nurses
- Clinical psychologists
- Palliative care services
- Respiratory services
- Cardiac services
- Wheelchair services
- Paid carers

Specialist equipment, housing adaptation and specialist accessible transport may all be required to maintain or develop independence. Other aids for mobility, bathing, independent living, communication and respiration may be required.

### The Muscular Dystrophy Campaign

MDC is the only UK charity focusing on all the muscular dystrophies and allied conditions and has pioneered the search for treatments and cures for over 45 years. The organisation campaigns to increase government spending on research, services and equipment.

MDC organizes fund-raising and condition-specific training days, working through its nationwide grass-roots network of Branches. It also produces a wide range of information on the conditions and related topics.

Details of local and national contacts plus allied support groups for the different types of Muscular Dystrophy can be found on [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) and the MDC Helpline can be contacted on 020 7803 4800 or [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org).

**NOTES**

## Appendix 1 – Demographic data

### Incidence and prevalence of neurological conditions in the South-West (extrapolated figures from those cited in Annex 4 of the NSF)

Condition	Incidence	Prevalence	Approximate total numbers <sup>3</sup>
Multiple sclerosis	3-7	100-120	5000-6000*
Motor Neurone Disease	2	7	350
Progressive Supra-nuclear palsy <sup>4</sup>		6	300
Parkinson's Disease	17	200	10000
Traumatic brain injury leading to long-term problems	175	1200	60000
Cerebral palsy	n/k	186	
Charcot-Marie-Tooth disorder	n/k	40	2000
Dystonia	n/k	65	3250
Early-onset dementia	n/k	n/k	n/k
Epilepsy	24-58	430-1000	2350-5000
Essential tremor	n/k	850	42500
Huntingdon's disease	n/k	13.5	675
Migraine	400	15000	750000
Muscular dystrophy	n/k	50	2500
Post-polio syndrome	n/k	200	10000
Spinal cord injury	2	n/k	n/k
Spina bifida and congenital hydrocephalus	n/k	24	1200
Young onset stroke	55	n/k	n/k

\* Figures for MS were revised upwards significantly in 2009 following research commissioned by the MS Society. Based on 2009 figures, it is likely that there are in excess of seven thousand people living with MS in the region.

<sup>3</sup> Based on a population for NHS South-West of five million

<sup>4</sup> Figures specifically for Supra-Nuclear Palsy not specified within the NSF. These prevalence figures based on information from the PSP Association

## Appendix 2 – The compilers

### Motor Neurone Disease Association

Hilary Fairfield	Regional Care Development Adviser
Bill Nevin	Regional Care Development Adviser
Mike McKeivitt	Regional Manager
Su Starkey	Volunteering Development Co-ordinator

### Multiple Sclerosis Society

Andrew Kemp	Service Development Officer
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### Parkinson's Disease Society

Neil Smart	Community Services Manager
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### Progressive Supra-Nuclear Palsy Association

Kathy Miller-Hunt	Regional Development Officer
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### Headway

Ali Bazley	Regional Co-ordinator
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### Stroke Association

Alan Bartle	Regional Manager
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### Huntington's Disease Association

Carol Dutton	Regional Care Advisor
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### Scope

Karin Gray	Regional Response Worker
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