

Yorkshire & the Humber Association  
of Neurological Organisations

**YHANO**



**Third Sector Neurological  
Organisations in Yorkshire  
and the Humber**



*'A wealth of knowledge and skills on your doorstep'*

**Version 5**

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# Introduction

## YHANO

### Yorkshire & the Humber Association of Neurological Organisations

YHANO is a collaborative group representing third sector neurological organisations in Yorkshire and the Humber. YHANO was set up in 2009 building upon the experience of the original VOWNnet (Voluntary Organisations Workers in Neurology Network). Membership is open to any employee of a neurological third sector organisation within the region, whose roles include a remit to influence health and social care service provision. It meets on a quarterly basis and has representatives from a range of the third sector neurological organisations included in this booklet.

*“Delivering improvements for people with long term conditions isn’t just about treating illness, it’s about delivering personalised, responsive, holistic care in the full context of how people live their lives.*

*Our journey to achieve this has started, our challenge is to continue to take it forward and the evidence compels us to do this.”*

Professor, David Colin-Thome, OBE

This directory has been compiled to provide a range of information about neurological conditions, a brief overview of the needs of people living with a long term neurological condition and to signpost to resources and services in Yorkshire and the Humber that can provide help, support and in some cases, rehabilitation for this group of people.

**What we do:-** Members of YHANO work together to:

- Engage with health & social care as a united group
- Work together on common neurological issues
- Collectively influence health & social care at a strategic level

**We make a difference by:**

- Working together
- Working effectively
- Sharing our knowledge
- Raising awareness

**Leading to a stronger voice for the million people (1 in 5) living with Long Term Neurological Conditions in Yorkshire & the Humber**

## In 2013/14:

We worked with Local Authority managers and Public Health Registrars across the region to ensure that neurological conditions are included in revised Joint Strategic Needs Assessments. We have worked with them to identify the evidence that they need to incorporate into their Health and Wellbeing Strategies. This will be an ongoing challenge.

We worked closely with the new Strategic Clinical Networks and Senate in Yorkshire & the Humber, contributing to regional scoping of neurological services, identification of key priorities for acute and chronic neurology, development of strategic care pathways and exploring opportunities for patient & public engagement

We worked with regional NHS Clinical Commissioning Groups and Social Care decision makers to raise the profile of long term neurological conditions and the role that our organisations can play as partners in the new integrated care pathways that are being developed. We have also engaged our volunteers in the newly formed HealthWatch and Patient and Public Engagement agendas.

We worked alongside our Neurological Alliance colleagues on a national and regional level to represent people living with long term neurological conditions in Yorkshire & the Humber and participated in local projects with Neurological Commissioning Support resulting in mapping of services and development of integrated care pathways

We delivered joint neurological study days aimed at non-specialist health and social care staff, providing information to help practitioners provide improved care. These included condition specific workshops that were devised following feedback from our previous events. Information stands relating to individual conditions were also provided and hosted by staff and local volunteers. The workshops were very well supported and we have further events planned for 2014/15.

We also responded to requests from individual organisations for bespoke neurological education, and continue to explore opportunities to provide education for those working in the field of long term neurological conditions

We developed our new website which hosts information about our group activities and contacts: [www.yhano.org.uk](http://www.yhano.org.uk)

We feel as a group that we have made a positive impact on the lives of people living with neurological conditions in the Yorkshire & the Humber region. Working together has improved our ability to reach further than we would individually and we will continue with our joint working strategy.

# Brain Injury

## The Condition

A Traumatic Brain Injury (TBI) is an injury to the brain caused by trauma to the head (head injury). There are many possible causes, including road traffic accidents, assaults, falls and accidents at home or work.

An Acquired Brain Injury (ABI) is an injury caused to the brain since birth and includes traumatic brain injury as well as tumour, stroke, brain haemorrhage and encephalitis, to name a few.

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 can have 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.

There were 353,059 admissions to hospital with acquired brain injury in 2011-12.

## Headway - The Brain Injury Association

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 - Freephone 0808 800 2244**, 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 provides both in house and open training courses including Understanding Brain Injury, Cognitive Rehabilitation And Sex And Sexuality

Following Brain Injury. Further details of training and courses and the Headway Certificate in Brain Injury can be gained by contacting our Training Manager: [training.manager@headway.org.uk](mailto:training.manager@headway.org.uk)

For information about, and to discuss the work of Headway within Yorkshire and the Humber, please contact Cerys Long on:

**Email:** [regional.coordinator@headway.org.uk](mailto:regional.coordinator@headway.org.uk)

**Tel:** 0795 151 7625

## **Service Delivery in Yorkshire and the Humber**

There are a number of Headway Groups and Branches in the region that provide various types of innovative support and signposting for people with brain injuries, their family and Carers.

### **Headway Barnsley**

**Tel:** 01226 295945 or 07788 590006 **Email:** [dc.bartrop@btinternet.com](mailto:dc.bartrop@btinternet.com)

**Headway Bradford** [www.headwaybradford.org.uk](http://www.headwaybradford.org.uk)

**Tel:** 07856 076866 **Email:** [headway\\_bradford@hotmail.co.uk](mailto:headway_bradford@hotmail.co.uk)

### **Headway Doncaster**

**Tel:** 0808 8002244 **Email:** [headwaydoncaster@gmail.com](mailto:headwaydoncaster@gmail.com)

**Headway Grimsby** [www.headwaygrimsby.btck.org.uk](http://www.headwaygrimsby.btck.org.uk)

**Tel:** 01472 316622 **Email:** [mark.griffin22@virginmedia.com](mailto:mark.griffin22@virginmedia.com)

### **Headway Huddersfield**

**Tel:** 07543 914431 **Email:** [headway.huddersfield@yahoo.co.uk](mailto:headway.huddersfield@yahoo.co.uk)

**Headway Hull and East Riding** [www.headwayhero.org.uk](http://www.headwayhero.org.uk)

**Tel:** 07538 319716 **Email:** [headwayhull@talktalk.net](mailto:headwayhull@talktalk.net)

### **Headway Leeds**

**Tel:** 07771 179792 **Email:** [headwayleeds@googlemail.com](mailto:headwayleeds@googlemail.com)

**Headway Rotherham** [www.headwayrotherham.co.uk](http://www.headwayrotherham.co.uk)

**Tel:** 01709 581828 **Email:** [info@headwayrotherham.co.uk](mailto:info@headwayrotherham.co.uk)

### **Headway Scunthorpe**

**Tel:** 01652 654 363 **Email:** [helloheadway@hotmail.co.uk](mailto:helloheadway@hotmail.co.uk)

### **Headway Sheffield**

**Tel:** 07849 338380 **Email:** [hello@headwaysheffield.co.uk](mailto:hello@headwaysheffield.co.uk)

**Headway Wakefield Second Chance** [www.schc.org.uk](http://www.schc.org.uk)

**Tel:** 01924 212951 **Email:** [info@schc.co.uk](mailto:info@schc.co.uk)

### **Headway York**

**Tel:** 07980 004397 **Email:** [headway\\_york@hotmail.co.uk](mailto:headway_york@hotmail.co.uk)

### **Headway Yorkshire East Coast**

**Tel:** 01302 308688 **Email:** [headwayeastcoast@hotmail.co.uk](mailto:headwayeastcoast@hotmail.co.uk)

# Brain Tumour

## The Condition

- Because of their location at the control centre for thought, emotion and physical function, brain tumours are difficult to treat.
- Brain tumours cause seizures, memory loss, deafness and lack of coordination to name just a few side effects.
- Currently, brain tumours cannot be prevented because their cause is still unknown.
- There are over 120 different types of brain tumours, making effective treatment very complicated.
- Brain tumours are currently treated by surgery, radiation therapy and chemotherapy.

## Prevalence

- Brain tumours have recently overtaken leukaemia as the most common malignancy and cause of death in children. There is a 5% to 10% annual increase in paediatric brain tumours.
- Around 4,500 new cases of primary brain tumours are diagnosed in the UK each year. In Yorkshire we saw 600 adults (with around 120 affected by the most aggressive high grade tumours) and 25 children as newly diagnosed patients in 2005.
- Lack of funding and research into the treatment of malignant brain tumours means survival rates are no better than they were 40 years ago.
- Brain tumours are the second most common cause of neurological death (stroke is the most common).

## Brain Tumour Research and Support across Yorkshire (BTRS)

Founded in 2003, originally named Andrea's Gift, BTRS is Yorkshire and Humber's leading brain tumour charity (Reg Charity 1095931) offering a holistic service across the region to all brain tumour patients, adults and children, as well as their families and carers, through support and research.

BTRS is committed to giving support to those in need throughout the challenges faced when diagnosed with a brain tumour; support ranges from physical interventions to online information, advice and guidance.

In addition BTRS co-fund, with Candlelighters, the Translational Neuro-Oncology Group at Leeds Institute of Molecular Medicine; without research there will be no improvement for brain tumour fighters.

We hold a support group meeting for patients and carers on the first Tuesday of the month. It is held at the Crowne Plaza Hotel, Wellington Street, Leeds, United Kingdom, LS1 4DL, from 6.30pm to 8.30pm. Refreshments provided.

For information about, and to discuss the work of BTRS within Yorkshire and the Humber, please contact:

Rachel Wilson, Charity Manager on:

07436 272 665

email: [rachel@btrs.org.uk](mailto:rachel@btrs.org.uk)

Our website is: [www.btrs.org.uk](http://www.btrs.org.uk)

Office Address:

Suite 21, The Tannery, 91 Kirkstall Road, Leeds, LS3 1HS.

## **Brainstrust**

*brainstrust* works across the UK helping brain tumour patients and carers to become involved and engaged in their care so that they can take control and be confident that they are working towards the best possible outcome for their situation.

All of *brainstrust's* support services have been designed by brain tumour patients and carers. We answer specific questions quickly and concisely over the phone and by email - day and night, and we help patients and carers pull together a broader, longer term programme of care themselves, by using our unique set of coaching skills.

*brainstrust's* ethos revolves around empowering patients and their carers, and creating a supportive community for those affected where they can interact as much, or as little, as they need to both in the real world and online.

The main website at [www.brainstrust.org.uk](http://www.brainstrust.org.uk) provides a whole range of clinically approved, Information Standard accredited content, and our Brain Tumour Hub ([www.braintumourhub.org.uk](http://www.braintumourhub.org.uk)) is the only UK database of brain tumour support services.

*brainstrust* offers a range of resources to help patients and carers get back on top of things. These include our unique 'brain box' and the 'Little brainstrust' website, the home of our dedicated support service for children and families.

Although help is available to patients and carers throughout Yorkshire and the Humber, people in Sheffield and South Yorkshire are the first to benefit from *brainstrust's* regionally focused support service. A key part of the new regional service are the informal 'Meet Ups' where the members of the brain tumour community can get to know each other informally and be reminded that they are not alone on their journey.

## **Regional Staff Contact Details:**

### **Pete Burchill**

Support Specialist (Sheffield and South Yorkshire)

Tel: 07741 316 277

*Email: [pete@brainstrust.org.uk](mailto:pete@brainstrust.org.uk)*

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### **National HQ and 24/7 Helpline**

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Castle Road  
Cowes  
Isle of Wight  
PO31 7QG

Tel: 01983 292405

*Email: [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk)*

# Epilepsy

## The condition

Epilepsy is a group of conditions that have epileptic seizures as a symptom. If you have epilepsy, it means you have had more than one epileptic seizure and could have more in the future.

Seizures can happen in any part of the brain. The brain is responsible for all the functions of our mind and body. What any of us experience during a seizure will depend on where in the brain the seizure is happening. Anyone can develop epilepsy at any time and although it can start at any age, it is more common in children and young people under 20 and people over 65.

## Symptoms

The symptom of epilepsy is epileptic seizures. Electrical activity is happening in the brain all the time. A seizure happens when there is a sudden burst of intense electrical activity. This intense electrical activity causes a temporary disruption to the way the brain normally works, meaning that the brain's messages become mixed up. The result is an epileptic seizure.

There are many different types of epileptic seizure, and some people have more than one type of seizure. Seizures are often put into two groups – focal (partial) seizures and generalised seizures. In focal seizures, the epileptic activity starts in just a part of the brain. People may remain alert during this type of seizure, or may not be aware of what is happening. People may have movements that they can't control, or unusual sensations or feelings. Sometimes, onlookers may not be aware that someone is having a seizure. Focal seizures can be very brief or last for minutes.

Sometimes epilepsy activity starts as a focal seizure, spreads to the rest of the brain and becomes a generalised seizure. Generalised seizures involve epileptic activity in both halves of the brain. People usually lose consciousness during this type of seizure, but sometimes it can be so brief that no one notices. The muscles may stiffen and/or jerk. They may fall down.

## Causes

In around six of out of 10 people, doctors don't know the cause of their epilepsy. For many of these people, it is just part of how they are made that makes them more likely to have a seizure.

Some people do have a cause for their epilepsy. One cause can be brain

damage. There are a number of things that can cause brain damage. These include:

- a difficult birth
- a brain infection, such as meningitis
- a stroke
- a serious brain injury

## Treatment

The most common way epilepsy is treated is with epilepsy medicines. Epilepsy medicines do not cure epilepsy, but aim to try to stop seizures happening. Epilepsy medicines are taken at regular times every day. Up to seven out of every 10 people with epilepsy, have their seizures fully controlled (are 'seizure free') with the right epilepsy medicines. For people whose epilepsy doesn't respond to epilepsy medicines, there may be other treatment options. These include vagus nerve stimulation, the ketogenic diet or brain surgery.

## Incidence

Approximately 600,000 people in the UK have epilepsy. This is equivalent to 1 in 103 people.

About one in every 220 children and young people aged 18 years and under has epilepsy; that's around 63,400 in this age group.

Around 87 people are diagnosed with epilepsy every day in the UK.

## Impact on Health & Social Care

Epilepsy affects people in different ways. Some people no longer have seizures because their epilepsy medicines stop them. So, their epilepsy has little impact on their lives. Other people still have seizures. These may affect their ability to drive, to work, or to make the most of their relationships, education, or leisure activities.

If a GP thinks a patient might have epilepsy, they will usually arrange for them to see an epilepsy specialist at the hospital to make sure they get the right diagnosis and have the best treatment. The epilepsy specialist is usually a neurologist (for adults) or a paediatrician (for children). There may be other specialists involved in treatment, such as epilepsy specialist nurse, learning disability specialists, psychologists or psychiatrists.

There are NICE clinical guidelines that set out the treatment and management for people with epilepsy. These are called 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. Some people with epilepsy and other associated or co-existing conditions or disabilities need some level of supported or residential care.

## **Epilepsy Action**

**Address:** New Anstey House  
Gate Way Drive  
Yeadon  
Leeds  
LS19 7XY  
**Tel:** 0113 210 8800  
**Fax:** 0113 391 0300

**North England Manager**  
Cliff Challenger  
Epilepsy Action  
PO Box 1082  
Bradford BD1 9LJ  
**Tel:** 01274 640064  
cchallenger@epilepsy.org.uk

**Epilepsy Helpline: Freephone 0808 800 5050**

**Freephone Text Helpline: 07537 410 044**

**E-mail:** helpline@epilepsy.org.uk

**Website:** www.epilepsy.org.uk

### **Freepost Address:**

Freepost RTGS-LEYK-XGCK  
Epilepsy Action  
New Anstey House  
Gate way Drive  
Yeadon  
LEEDS LS19 7XY

Epilepsy Action is the leading organisation working with and for people affected by epilepsy. Each year, Epilepsy Action helps around one million people understand epilepsy and treatment options through its helpline, website and events. The charity improves healthcare by supporting epilepsy specialist nurses and epilepsy research. It improves the lives of everyone affected by epilepsy by campaigning for better healthcare and fairer access to education and employment. The Epilepsy Helpline (Freephone 0808 800 5050) is available Monday-Friday, 9.00 am - 4.30pm (4.00 pm on Fridays).

**Registered Charity: 234343**

## **The Epilepsy Society**

### **Head office**

The Epilepsy Society

Chesham Lane

Chalfont St Peter

Bucks SL9 0RJ

Helpline: 01494 601 400

**Web:** [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

Charity number 206186

### **Regional Manager East Midlands**

(Includes South & East Yorkshire and Northwest)

#### **Zelma Hutchinson**

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[zelma.hutchinson@epilepsysociety.org.uk](mailto:zelma.hutchinson@epilepsysociety.org.uk)

### **Regional Manager North**

#### **Dee Moore**

Tel: 01912520504 / 01494 601 316

[dee.moore@epilepsysociety.org.uk](mailto:dee.moore@epilepsysociety.org.uk)

The Epilepsy Society's mission is to enhance the quality of life for people affected by epilepsy, by promoting research, education and public awareness and by delivering specialist medical care and support services.

# 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 but symptoms such as depression, mood-swings and involuntary movements can be reduced by prescribed drugs. Research is carried out throughout the country

## Incidence and Prevalence

- 1 in 10,000 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 identify suitable respite breaks, and residential and other services such as specialist clinics and day centres. We also provide training sessions aimed at health and social care.. 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 0151 331 5444.

### **Regional Care Advisors:**

#### **North & East Yorkshire:**

##### **Contact Head Office**

**Tel:** 0151 331 5444

**Email:** [info@hda.org.uk](mailto:info@hda.org.uk)

#### **Bassetlaw, South Yorkshire and West Yorkshire under the M62:**

##### **Diana King**

**Tel:** 0114 287 3209

**Email:** [diana.king@hda.org.uk](mailto:diana.king@hda.org.uk)

#### **Cheshire, Manchester and West Yorkshire above the M62:**

##### **Debra Robinson**

**Tel:** 0161 3032966

**Email:** [debra.robinson@hda.org.uk](mailto:debra.robinson@hda.org.uk)

# Migraine

## The Condition

Migraine is a complex condition with a wide variety of symptoms. For many people the main feature is a painful headache. Other symptoms include disturbed vision, sensitivity to light, sound and smells, feeling sick and vomiting. Migraines can be very frightening and may result in you having to lie still for several hours. The symptoms will vary from person to person and individuals may have different symptoms during different attacks. Your attacks may differ in length and frequency. Migraines usually last from 4 to 72 hours and most people are free from symptoms between attacks. Migraines can have an enormous impact on your work, family and social lives.

There is no known cause for migraine, although most people with it are genetically predisposed to migraine. If you are susceptible to migraine there are certain triggers which commonly occur. These include stress, lack of food, alcohol, hormonal changes in women, lack of sleep and the environment.

Among adults of all ages, migraine is one of the top 20 causes of disability expressed as years of healthy life lost to disability (The World Health Report 2001, WHO) Severe migraine attacks are classified by the World Health Organisation as among the most disabling illnesses, comparable to dementia, quadriplegia and active psychosis (Shapiro & Goadsby, Cephalalgia, September 2007)

## Prevalence:

- Migraine affects more than 1 in 7 people in the UK
- There are an estimated 8 million people with migraine in the UK
- In the UK, there are an estimated 190,000 migraine attacks every day (Steiner et al, Cephalalgia, 2003)
- Women are more likely to have migraine attacks than men – 18% of women and 8% of men (Steiner et al, Cephalalgia, 2003)
- Migraine remains undiagnosed and undertreated in at least 50% of patients, and less than 50% of migraine patients consult a physician (Pavone, Banfi, Vaiani & Panconesi, Cephalalgia, September 2007)

## **Impact on Health and Social Care Services:**

Headache is the commonest neurological symptom presented to GPs and 4% of all adults consult a GP for headache each year (Latinovic, Gulliford, Ridsdale, J Neurol Neurosurg Psychiatry 2006)

A survey of neurologists found that up to one-third of all patients consulted because of headache – more than for any other complaint (WHO, Factsheet 277, March 2004)

Migraine is the least publicly funded of all neurological illnesses relative to its economic impact (Shapiro & Goadsby, Cephalalgia, September 2007)

## **The Migraine Trust**

The Migraine Trust is the health and medical research charity for migraine in the United Kingdom. We are committed to supporting people living with migraine by providing them and their families with evidence based information. We seek to raise awareness of migraine as a serious public health issue. The Migraine Trust funds and promotes research into migraine in order to better understand it, to improve diagnosis and treatment and ultimately to find a cure for this debilitating condition.

The Migraine Trust  
52-53 Russell Square  
London  
WC1B 4HP  
[www.migrainetrust.org](http://www.migrainetrust.org)

Information and Enquiry Service: We can help with questions you may have about migraine, other headaches and their management. All our information is based on the best available evidence.

Telephone: 020 7631 6975

Email: [info@migrainetrust.org](mailto:info@migrainetrust.org)

Advocacy Service: We can provide advocacy support to empower migraine sufferers to assert their rights and claim their entitlements in the areas of healthcare, employment and education.

Telephone: 020 7631 6973

Email: [advocacy@migrainetrust.org](mailto:advocacy@migrainetrust.org)

# 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.
- Most people diagnosed with the disease are over 40, with the highest incidence occurring between the ages of 50-70
- 50% of all people die within 14 months of diagnosis
- MND is characterised by progressive muscle wasting and weakness, with the muscles affected varying in each individual. Symptoms can include loss of limb function, leaving people unable to walk or use their hands and arms, loss of speech and swallowing, inability to breathe and some people may experience cognitive change.

## Incidence and prevalence

The incidence of MND is approximately two per 100,000, which suggests that there may be 100 new cases of MND diagnosed every year in Yorkshire & the Humber. The prevalence of MND is approximately seven per 100,000, suggesting that there are approximately 350 people currently living with MND in Yorkshire & the Humber.

## 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 team
- Paid carers – for direct care and also for carer respite

Multiple items of specialist equipment are likely to be required (eg. specialised wheelchairs, non-invasive ventilators, suction machines, environmental controls, communication aids etc). In the latter stages, funding is frequently required from Continuing Health Care budgets.

## The MND Association

The MND Association funds and promotes 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 (RCDAs) working in Yorkshire and the Humber, plus a Volunteering Development Co-ordinator and a team of trained volunteer Association Visitors. RCDAs offer an additional level of expertise and support, when required, in more complex situations, whilst on-going support for people with MND and their families can be provided through the network of Visitors. There is also a network of local branches and support groups throughout the region that support people affected by MND, raise funds, provide information and financial assistance, campaign and raise awareness of MND.

The MND Association financially supports locally based MND services through its national programme of MND Care Centres.

### **MND Care Centres/Networks provide:**

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

In Yorkshire and the Humber, the 3 MND Care Centres are at the Royal Hallamshire Hospital, Sheffield, Leeds General Infirmary and James Cook University Hospital, Middlesbrough.

Further information about any aspect of MND and the work of the Association is available from

MND Connect advice and support service - **08457 626262**.

National Office: PO Box 246, Northampton, NN1 2PR, Tel: 01604 250505

**[www.mndassociation.org](http://www.mndassociation.org)**

## **Regional Care Development Advisers**

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## **Volunteering Development Co-ordinator**

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# 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 (MS Society, 'Strength in Numbers' 2009)
- The prevalence of MS in Yorkshire & the Humber region is approximately 200 per 100,000 (MS Society 2009)
- Mid-2005 population estimates published by the Office for National Statistics in August 2006, suggest that there are currently 10,400 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 health and social care professionals including:

- Neurology consultants
- Specialist nurses
- Occupational therapists
- Physiotherapists
- Continence advisory and management services
- Dieticians
- Pain management services
- Chiropody and podiatry
- Ophthalmology services

- Speech and language therapists
- Clinical psychologists
- Social workers
- 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 and provides financial assistance and 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 Yorkshire & the Humber area working alongside people affected by MS and health and social care professionals, and one salaried local support development officer working mainly with branches. They are supported by an Area Manager covering the whole of the North of England

There are eighteen branches and support groups in Yorkshire & the Humber providing information and local support for people affected by MS and their families and carers. These are run by volunteers:

Barnsley & District

Bridlington & District

Halifax & Calder Valley

Harrogate & District

Hull, Beverley Borough & Holderness

Bradford & District

Doncaster & District

Hambleton & Richmond

Huddersfield & Kirklees

Leeds & District

Rotherham & Sheffield

Scarborough & District

Settle & District

Wakefield & District

Ryedale

Scunthorpe & District

Skipton & Craven

York & District

Contact details for all branches can be found at: **[www.mssociety.org.uk](http://www.mssociety.org.uk)**.

**Regional staff contact details:**

**Liz Wilde**

Service Development Officer  
Officer

Tel: 020 8438 0933

Email: [Liz.Wilde@mssociety.org.uk](mailto:Liz.Wilde@mssociety.org.uk)  
org.uk

**Jeremy Harris**

Local Support Development  
Officer

Tel: 020 8438 0865

Email: [Jeremy.Harris@mssociety.org.uk](mailto:Jeremy.Harris@mssociety.org.uk)

**Abby Caskie**

Area Manager

Tel: 020 8438 0884

Email: [Abby.Caskie@mssociety.org.uk](mailto:Abby.Caskie@mssociety.org.uk)

**National Address:**

MS Society

372 Edgware Road

London NW2 6ND

Tel: 020 8438 0700

Website: **[www.mssociety.org.uk](http://www.mssociety.org.uk)**

# Parkinson's Disease

Parkinson's is a progressive neurological condition. There are more than 10,000 people affected in Yorkshire and the Humber. That's about 127,000 in the UK (28 people with Parkinson's disease in every 10,000 of the population). This figure will rise to 162,000 in 2019 (based on present population trend figures). Most people who get Parkinson's are aged 50 or over but younger people can get it too. One in 20 is under the age of 40. People with Parkinson's don't have enough of a chemical called dopamine because some nerve cells in their brain have died. Without dopamine people can find that their movements become slower so it takes longer to do things. The loss of nerve cells in the brain causes the symptoms of Parkinson's to appear. There's currently no cure for Parkinson's and we don't yet know why people get the condition. Parkinson's doesn't directly cause people to die, but symptoms do get worse over time.

Parkinson's UK bring together people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We campaign to change attitudes and demand better services. Our work is totally dependent on donations.

**Parkinson's UK, 215 Vauxhall Bridge Road, London, SW1V 1EJ**

Free confidential helpline **0808 800 0303** (from UK landlines)

Visit us online at **[www.parkinsons.org.uk](http://www.parkinsons.org.uk)**

**For general enquiries in Yorkshire & the Humber please contact the Regional Manager**

**Regional Manager**

**Tel:** 0844 225 3630

**Email:** [rm.yorkshire@parkinsons.org.uk](mailto:rm.yorkshire@parkinsons.org.uk)

## Services in Yorkshire & the Humber

We have a dedicated team of information support workers in Yorkshire & Humber who can help answer your questions, and who provide free one-to-one support to people with Parkinson's, their families and carers. You can contact them via the Information Support Manager who will let you know the most appropriate member of the team to speak to:

## **Information Support Manager**

**Tel:** 0844 225 3632

**Email:** [ism.yorkshire@parkinsons.org.uk](mailto:ism.yorkshire@parkinsons.org.uk)

We have local groups and branches in many areas of Yorkshire which provide an opportunity for people to come together socially for mutual support. The Branch & Volunteer Support Officer will direct you to the group nearest to you. The groups are all run by volunteers so there are also many opportunities to volunteer too.

## **Branch & Volunteer Support Officer**

**Tel:** 0844 225 3634

**Email:** [bvso.yorkshire@parkinsons.org.uk](mailto:bvso.yorkshire@parkinsons.org.uk)

We campaign to make sure that people living with Parkinson's have access to services that are appropriate for their needs and are treated fairly. We want everyone to get high quality health and social care and work with professionals to improve services contact our Influence & Service Development Officer for further information;

## **Influence & Service Development Officer**

**Tel:** 0844 225 3633

**Email:** [isdo.yorkshire@parkinsons.org.uk](mailto:isdo.yorkshire@parkinsons.org.uk)

We provide a comprehensive range of training packages for health and social care professionals towards a better understanding of Parkinson's and the issues that are faced by people with the condition, for further information contact our Education & Training Officer;

## **Education & Training Officer**

**Tel:** 0844 225 3631

**Email:** [eto.yorkshire@parkinsons.org.uk](mailto:eto.yorkshire@parkinsons.org.uk)

Because all of our work is entirely funded by voluntary donations we have a regional fundraiser to help with ideas for planning events and supporting our fundraising volunteers. For further information or to donate please contact.

## **Regional Fundraiser**

**Tel:** 0844 225 9842

**Email:** [rf.yorkshire@parkinsons.org.uk](mailto:rf.yorkshire@parkinsons.org.uk)

**“Because we are here, no one has to face Parkinson's alone”**

# **Progressive Supranuclear Palsy (PSP) and Cortico Basal Degeneration (CBD)**

## **The condition**

- PSP a progressive neurological disease
- There is currently no known cure or treatment to slow the progress of the condition
- The mean age at onset of symptoms is 62 years, though people have been diagnosed as young as 40.
- Lifespan after the onset of first symptoms varies widely but averages between 5 and 7 years. There can be a delay in diagnosis – often first diagnosed at Parkinson’s Disease or frontal lobe Dementia or stroke.
- Symptoms are varied and complex - include falls (often backwards,) difficulties with speech, swallowing, slowing and limiting of vision, continence, rigidity and mobility. The intellect generally, but not always, remains intact although there can be other cognitive impairments including considerable apathy and lack of engagement and some people experience behavioural changes.

## **Cortico Basal Degeneration – similar to PSP except**

- Numbness, jerking fingers, loss of use of one hand
- Asymmetric; progressively affecting arm and leg
- Alien limb
- Less common disturbance of eye movement
- Increased frontal lobe deficit
- Even more rare

## **Prevalence**

Published research (2001) funded by The PSP Association suggests 6.4 cases of PSP per 100,000 in the UK. So approximately 300 or so in Yorkshire and the Humber. However misdiagnosis currently seriously affects of the number of people identified as living with PSP.



# Stroke

## The condition

- Stroke is the 3rd most common cause of death in the UK and the single most common cause of complex disability.
- A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off. Without a blood supply brain cells can be damaged or destroyed. The brain controls everything we do and so damage to the brain will affect body functions. It also controls how we think, learn, feel and communicate.
- A stroke is sudden and the effects on the body are immediate.

## Incidence and Prevalence

- Around 152,000 people have a stroke each year in the UK. That's one person every 5 minutes.
- 25% of strokes occur in people aged under 65 years.
- 40% of strokes are preventable by having regular blood pressure checks and changing lifestyle habits.

## The Impact on Health and Social Care Services

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
- Clinical Psychologists
- Speech and language therapists, Dieticians
- Occupational therapists, Physiotherapists

Some stroke survivors may require a range of equipment to maintain their independence such as wheelchairs and other mobility aids, bathing equipment, communication aids and others.

## 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. We fund research, provide commissioned services, Life After Stroke Grants, education and training on stroke.
- We campaign to raise awareness of stroke.
- We produce a wide range of publications on all aspects of stroke and its effects. These are available to download on our website or order from the helpline.
- Helpline - **0303 3033100**
- Website - **[www.stroke.org.uk](http://www.stroke.org.uk)**
- The regional office for Yorkshire & The Humber - **Tel: 0113 2019 792**

# Tourette Syndrome

## About Tourette Syndrome (TS)

TS is an inherited neurological condition. It affects one schoolchild in every hundred and more than 300,000 children and adults in the UK. The key feature is tics, involuntary and uncontrollable sounds and movements.

TS is sometimes known as multiple tic disorder or tic spectrum disorder.

In most cases TS is also linked to other behaviours, most often Obsessional Compulsive Disorder and Attention Deficit Disorder.

### **90 percent of people with TS do not swear uncontrollably (coprolalia).**

TS starts in childhood. For about half of children with TS, the condition continues into adulthood.

## Symptoms

The symptoms of Tourette Syndrome (TS) are tics, repeated movements and sounds. It is important to understand that these are chronic (long-term) and involuntary. Someone with TS may be able to suppress them for a period but eventually they have to let the tics out.

***'People with TS feel an irresistible urge to perform their tics as the average person would want to scratch an itch. Some are able to suppress their tics, maybe even for hours, but this will lead to a stronger outburst once they allow themselves to tic freely.'***

Tics usually start in childhood around the age of seven, and are usually worst between 10-12 years. However, in approximately half of TS patients, most symptoms disappear by the age of 18. TS is a persistent disorder but not always greatly disabling.

The first tics often start around the head and face, like blinking and/or grimacing. Vocal tics tend to appear later, around age 11. The different symptoms can be simple, such as blinking, or complex, like touching or jumping. Examples of vocal tics besides uttering words or making sounds are throat clearing, sniffing and/or coughing.

Even within the same person, the tics vary in many ways:

- they wax and wane; they get better and worse over time
- they change; one tic stops and another starts
- they may be made worse by stress and anxiety
- they may be alleviated with relaxation or concentration on an absorbing task

These changes are completely unpredictable. However, just before a tic is about to happen it is common to experience so called premonitory sensations. These sensations can be either localised - in the area where the tic is about to happen - or generalised. It is often very difficult, even for family, friends, teachers and employers of a person with TS, to believe that their actions or vocal utterances are involuntary, but they are.

Over 85 percent of people with TS have more than just tics. Additional conditions ('comorbidities') include obsessive compulsive disorder (OCD) and/or attention deficit hyperactivity disorder (ADHD). Children and adults may also suffer from 'rages'. Co-morbidities often present more problems than the tics and can be less visible.

For help, support and further information please contact:

Tourettes Action, Kings Court, 91-93 High Street, Camberley, Surrey GU15 3RN

**Helpline:** 0300 777 8427  
**Email:** [help@tourettes-action.org.uk](mailto:help@tourettes-action.org.uk)  
**Support Groups:** [julie@tourettes-action.org.uk](mailto:julie@tourettes-action.org.uk)  
**Website:** [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk)



Yorkshire & the Humber Association  
of Neurological Organisations



Representing people with neurological  
conditions across the region

 [enquiries@yhano.org.uk](mailto:enquiries@yhano.org.uk)

[http:// www.yhano.org.uk](http://www.yhano.org.uk)

Associated to the Neurological Alliance  
– a national forum of neurological charities

The printing of this edition was supported by an  
educational unconditional grant from Biogen Idec