



# **Information for unpaid carers and professionals**

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# Information for unpaid carers and professionals



**This leaflet provides information and support for carers of people with neurological conditions and professionals offering support to carers.**

Supporting someone with a neurological condition can be particularly challenging for unpaid carers. Conditions that impact the brain, spine and nervous system are very varied, and can have a wide range of impacts. Many conditions are poorly understood and have limited treatments. Access to care and support can also be very complicated and services are often lacking.

This leaflet is to signpost unpaid carers and those who work in carer centres across Scotland to the right support.

Within the leaflet you will find:

1. **Neurological conditions A-Z** (*list of neurological conditions that are supported by member charities of the Neurological Alliance of Scotland*)
2. **General neurological therapy centres and support networks** (*broader support for neurological conditions from members of the Neurological Alliance of Scotland*)
3. **Local Carer Centres** (*listed alphabetically by region*)
4. **National Carer Organisations**
5. **Further information and resources**
6. **Directory of our charity members**

If you need advice and support for a condition that is not listed in this factsheet, please visit [NHS Inform](#).

Click on any of the charity links to find out more about the conditions listed and the support and services that you can access.

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### **You are a carer – how can we help?**

Being an unpaid carer is a unique role and you probably know more about the person you care for than anyone else. Sometimes it's difficult to be confident that someone else will do as good a job as you at looking after the person you care for. It is perfectly ok to ask for help sometimes, local carer organisations are there to support and guide you.

Each local authority across Scotland will have a service commissioned to support unpaid carers. Your local centre will provide you with a variety of information including resources to support your wellbeing, advice on finances, health and social care supports, emergency planning, advocacy and how to access an adult carer support plan. You can find your nearest carers centre in Section 3.

Each of our members in this list offer support for carers from information, advice, support groups, helplines or other services.

### **You are a professional- how can we help?**

This resource is designed to help you confidently signpost unpaid carers to condition specific services and local carer organisations.

This list is not exhaustive of every neurological condition (there are over 600 known neurological conditions), but representative of members of the Neurological Alliance of Scotland.

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## 1. Neurological conditions A-Z

### Ataxia


Ataxia is a term for a group of neurological conditions that affect balance, coordination and speech. Any part of the body can be affected by ataxia and it can affect people in different ways.

 [Ataxia UK](#)

### Brain injury

An acquired brain injury (ABI) is an injury caused to the brain since birth. There are many possible causes, including a fall, a road accident, tumour and stroke.

 [Child Brain Injury Trust](#)

 The Headway Group:  
[Dundee and Angus](#)  
[Edinburgh](#)  
[Glasgow](#)  
[Headway UK](#)

 [Scottish Head Injury Forum](#)

### Brain tumour

Brain tumours are a complex disease and both low and high grade tumours can have lifelong consequences on those affected including personality changes, memory loss and regular headaches.

 [The Brain Tumour Charity](#)

 [brainstrust](#)

### Cerebral palsy

Cerebral palsy is a condition caused by either damage to the brain, or abnormal development of the brain. This damage normally occurs before birth or during a child's early development. Cerebral palsy usually causes abnormal muscle tone and movement. Although cerebral palsy is not progressive, a person's presentation of the condition may change with growth and ageing.

 [Cerebral Palsy Scotland](#)

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## Dementia

Dementia is an umbrella term that describes a complex set of disease processes that are impacting on a person's brain. There are many different types of dementia. Symptoms may include forgetfulness and confusion, sensory impairment, personality changes, difficulties with day-to-day tasks and problem solving.

 [Alzheimer Scotland](#)

## Dystonia

Dystonia is a neurological movement disorder that is estimated to affect at least 100,000 people in the UK. People with dystonia experience involuntary muscle spasms and contractions.


 [Dystonia UK](#)

## Epilepsy

Epilepsy is defined as the tendency to have repeated seizures which start in the brain.

 [Epilepsy Connections](#)

 [Epilepsy Scotland](#)

 [William Quarrier Scottish Epilepsy Centre](#)

## Essential tremor

Essential tremor is considered one of the most common neurological movement disorders and is estimated to be eight to ten times more prevalent than Parkinson's disease. People exhibit a rhythmic trembling of the hands, head, legs, trunk and/or voice.

 [Scottish Tremor Society Facebook Support Group](#)

## Functional neurological disorder (FND)


Functional neurological disorder (FND) is a problem with the functioning of the nervous system and how the brain and body send and receive signals.

 [FND Hope](#)

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## Guillain-Barré and associated inflammatory neuropathies

Guillain-Barre is a rare and serious inflammatory neuropathy that damages the peripheral nerves. It affects one to two people per 100,000 per year. There are also around 1,000 people each year diagnosed with Chronic inflammatory demyelinating polyneuropathy (CIDP) and Multifocal motor neuropathy (MMN).

 [Guillain-Barré and Associated Inflammatory Neuropathies \(GAIN\) charity](#)

## Headaches and migraines

Migraine is a severe and 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, smells, feeling sick and vomiting.

 [The Migraine Trust](#)

## Huntington's disease

Huntington's disease is caused by an inherited faulty gene that damages the brain over time. People with the disease can eventually lose the ability to walk, talk, eat, drink and care for themselves, requiring specialist support from those who understand the condition. Anyone with a parent who has Huntington's has a 50% risk of inheriting the condition from them.

 [Scottish Huntington's Association](#)

## Motor neurone disease (MND)

Motor neurone disease (MND) is a rapidly progressing terminal neurological illness, which stops signals from the brain reaching the muscles. This causes muscle weakness and wasting. The average life expectancy of someone with MND is just 18 months from diagnosis.

 [MND Scotland](#)

 [My Name's Doddie Foundation](#)

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## Multiple sclerosis

Multiple sclerosis (MS) is a condition that affects your brain and spinal cord. In MS, the coating that protects your nerves (myelin) is damaged. This causes a range of symptoms like blurred vision and problems with how we move think and feel.

 [MS Centre Mid Argyll](#)

 [MS Society](#)

 [MS Therapy Centre Tayside](#)

 [MS Trust](#)

 [Revive MS Support](#)

## Multiple system atrophy (MSA)

Multiple system atrophy (MSA) is a progressive neurological disorder that affects adult men and women. It is caused by degeneration or atrophy (shrinking) of nerve cells in several (or multiple) areas of the brain. This can result in problems with multiple bodily functions.

 [MSA Trust](#)

## Muscular dystrophy

The term 'muscular dystrophy' defines a group of genetic muscle conditions with progressive skeletal muscle weakness and wasting caused by degeneration of muscle cells.

 [Muscular Dystrophy UK](#)

## Myalgic Encephalomyelitis (M.E)

The hallmark feature of the disabling chronic illness Myalgic Encephalomyelitis (M.E) is post-exertional malaise. Any physical, mental, emotional or sensory activity/stimulation can make symptoms worse, with impact often delayed. Around one in four children/adults with ME are house/ bedbound. All must carefully manage their limited energy; reablement is not appropriate.

 [Action for ME](#)

 [ME Association](#)

 [#MEAAction](#)

 [25% ME Group](#)



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## Myasthenia

This includes myasthenia gravis, ocular myasthenia, CMS, and LEMS. The myasthenias are a group of neuromuscular conditions. They are rare but also manageable. You aren't alone, myasthenia can affect anyone, old or young and of any gender or nationality.



## Narcolepsy

Narcolepsy is a rare neurological condition affecting the brain's ability to regulate sleep-wake cycles. Symptoms such as disturbed night-time sleep and excessive daytime sleepiness are regular. Cataplexy is a symptom causing weak muscle tone brought on by heightened emotions. Often considered a sleep disorder, its underlying cause means a better classification is a disorder of the central nervous system.



## Orthostatic tremor

Orthostatic tremor is a progressive neurological condition in which the initial symptoms present a rapid shaking of the legs when standing unsupported and can move upwards, decreasing body stability. It affects mobility and limits a person's ability to perform everyday tasks in an upright position.





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## PANS/PANDAS

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) are post-infectious disorders in which severe symptoms of obsessive-compulsive behaviours, tics or eating restrictions develop suddenly and are often accompanied by other mental and physical health symptoms.

 [PANS PANDAS UK](#)

## Parkinson's

Parkinson's is a progressive neurological condition. This means that it causes problems in the brain and gets worse over time. There are over 40 symptoms of Parkinson's. From a tremor or stiffness, to problems with sleep and mental health.

 [Parkinson's UK Scotland](#)

## Post polio syndrome

Post-Polio Syndrome is a poorly understood condition that can affect people who have had polio in the past.

 [British Polio Fellowship](#)

 [Scottish Post Polio Network](#)

## Progressive supranuclear palsy

Progressive Supranuclear Palsy, or PSP, is a rare neurological condition that progressively impacts balance, movement, vision, speech, and cognition.

 [PSPA](#)

## Spina bifida and hydrocephalus

Spina bifida is when a baby's spine and spinal cord do not develop properly in the womb, causing a gap in the spine. Hydrocephalus is a build-up of fluid in the brain. The excess fluid puts pressure on the brain, which can damage it.

 [Spina Bifida Hydrocephalus Scotland](#)

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### **Tourette's syndrome**

Tourette's syndrome is a complex neurological condition. Tourette's comprises of vocal and motor tics. These tics are involuntary and are not representative of the individual's thoughts, feelings, or an insight into their inner world. Many people with Tourette's will also have co-existing conditions such as DHD, OCD, Anxiety, and ASD.

 [Tourette Scotland](#)


### **Transverse myelitis**

Transverse myelitis is a rare neurological condition. It's caused by inflammation (swelling) of the spinal cord. The swelling damages the nerves and can leave permanent scars or lesions.

 [Siegel Rare Neuroimmune Association](#)

### **Vitamin B12 deficiency**

B12 (also known as cobalamin) is a vitamin which plays a part in the integrity of every cell in the body, therefore it is essential to all systems within the body. Its key roles are in the production of red blood cells which carry oxygen around the body, healthy functioning of the brain and nervous system, and the construction of DNA. Therefore any part of the body can suffer the effects of deficiency, from your DNA through to your mental well being.

 [The B12 Society](#)

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## 2. General neurological therapy centres and support networks

Broader support for neurological conditions from **members of the Neurological Alliance of Scotland** can be found in the directory below.

### **Brain and Spine Foundation**

The Brain and Spine Foundation is a UK-based organisation aiming to transform the daily reality of each person affected by any neurological condition, as well as their family, friends and carers. The foundation is committed to improving services across the whole spectrum of neurological conditions, as well as recognition and awareness of the impact of these conditions.

### **The Craighalbert Centre**

The Craighalbert Centre works with families and partners to enable children in Scotland with neurological conditions to achieve their potential and fulfil their ambitions through delivery of integrated learning, therapy and care services and training. Programmes address the multiple and complex needs of children from birth to 19 years with a suspected or confirmed diagnosis, providing a range of child and family-centred programmes delivered by highly specialist physiotherapists, occupational therapists, speech and language therapists, teachers, and care and therapy practitioners.

### **The Dochas Carers Centre**

The Dochas Carers Centre provides information and guidance for carers across Mid Argyll, Kintyre, Islay and Jura. Their services include carer support, counselling, befriending, carer information and training, and funding for short breaks. All services are free for unpaid carers.

### **Funding Neuro**

Funding Neuro aims to accelerate the development of new treatments for many of the most serious neurological conditions. Funding Neuro focusses on pre-clinical and applied research and undertakes clinical trials across a range of conditions with the aim that they lead to new recognised treatment options. They advocate for better treatment for neurological conditions and work with the NHS and other care providers, universities, government, industry, philanthropists and other charities.

### **Compass Therapy Support Community**

Compass provides therapy and advice to support the wellbeing of those with neurological conditions in the Lothians. They provide specialist neurological physiotherapy, rehabilitation and wellbeing services, complimentary therapies and oxygen therapies.

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## **Neuro Central**

Neuro Central is based in Central Scotland and aims to advance the health and wellbeing of people who live with neurological conditions through access to high quality services and therapies, information and support for them, their carers, and their families in a friendly relaxed environment, so nobody has to feel alone.

## **Neuro Hebrides**

Neuro Hebrides provides a community for shared experience and understanding for those living with or caring for someone with a neurological condition in the Western Isles. They offer regular opportunities to meet with others and to take part in a range of activities tailored for those living with a neurological condition.

## **Neuro Therapy Network**

Neuro Therapy Network is a registered charity and membership organisation that represents a thriving group of independent therapy centres throughout Great Britain, and in Gibraltar and Jersey. They provide support, training, and operational guidance to centres, as well as promoting their work nationally so that more people living with neurological and other life-limiting conditions can access their services.

## **The Oxygen Works**

The Oxygen Works is a highland based centre which offers access to unique, innovative and holistic therapies and services, supporting the community to better manage their health and wellbeing. From oxygen therapy to physiotherapy and a range of complementary therapies; all aimed at offering clients choice in their health and wellbeing journey.

## **Sue Ryder**

Sue Ryder is a UK charity that aims to make sure everyone approaching the end of their life or living with grief can access the support they need. They offer palliative care, Online Bereavement Support services as well as carrying out influencing work and information for healthcare professionals.

## **The Thistle Foundation**

The Thistle Foundation's Health and Wellbeing team supports people with long-term health conditions or facing challenging life situations, to achieve what matters most to them through 1:1 wellbeing support, group based activities and peer support. They are based in Edinburgh, the Lothians and Fife.

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## 3. Local Carer Organisations

Whether you are new to caring or have been looking after someone else for some time now, it's important to know what your rights are. Each of the 32 Local Authority areas in Scotland provides support to unpaid carers through carer centres who are there to help you access support and understand your rights as a carer.

Below is a directory of the current carer centre by region. For where to find your nearest carer centre and the most up to date contact information, please visit: [Carers Information Scotland, carer centres](https://www.carersinformation.scot.nhs.uk/).

Name of Carer Centre	Region
Aberdeen Young Carers	Aberdeen City
Quarriers Aberdeen City Carers Support	Aberdeen City
Quarriers Aberdeenshire Carer Support Service	Aberdeenshire
Angus Carers Centre	Angus
Crossroads Cowal and Bute Carers Centre	Argyll and Bute
Dochas Carers Centre	Argyll and Bute
Helensburgh and Lomond Carers Centre	Argyll and Bute
Kintyre Young Carers	Argyll and Bute
Mid Argyll Youth Development Service	Argyll and Bute
North Argyll Carers Centre	Argyll and Bute
Borders Carer Centre	Borders
Borders Young Carers	Borders
Central Carers Centre	Clackmannanshire
Dumfries and Galloway Carers Centre	Dumfries and Galloway
Dundee Carers Centre	Dundee
East Ayrshire Carers Centre	East Ayrshire
Carers Link	East Dunbartonshire

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Name of Carer Centre	Region
Bridges Project	East Lothian
Carers of East Lothian	East Lothian
East Lothian Young Carers	East Lothian
East Renfrewshire Carers Centre	East Renfrewshire
Capital Carers	Edinburgh
Care for Carers	Edinburgh
Edinburgh Young Carers	Edinburgh
Space	Edinburgh
VOCAL Edinburgh Carers	Edinburgh
Yolo Sistas	Edinburgh
Central Carers Centre	Falkirk
Fife Carers Centre	Fife
Fife Young Carers	Fife
Glasgow East End Community Carers	Glasgow
Glasgow North End Carers Centre	Glasgow
Glasgow South East Carers Centre	Glasgow
North West Quarriers Glasgow	Glasgow
South West Glasgow Carers Centre	Glasgow
West Glasgow Carers Centre	Glasgow
Connecting Carers	Highland
Tykes Young Carers	Highland
Skye & Lochalsh Young Carers	Highland
Caithness Kills Young Carers	Highland
Inverclyde Carers Centre	Inverclyde
Inverclyde Young Carers	Inverclyde
Midlothian Young Carers	Midlothian
VOCAL Midlothian Carers Centre	Midlothian
Quarriers Carer Support Service (Moray)	Moray
North Ayrshire Carers Centre	North Ayrshire
Lanarkshire Carers	North Lanarkshire



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Name of Carer Centre	Region
North Lanarkshire Carers Together	North Lanarkshire
North Lanarkshire Young Carers	North Lanarkshire
Crossroads Caring for Carers	Orkney
Perth & Kinross Carers Centre	Perth & Kinross
Renfrewshire Carers Centre	Renfrewshire
Voluntary Action Shetland	Shetland
South Ayrshire Carers Centre	South Ayrshire
Lanarkshire Carers	South Lanarkshire
South Lanarkshire Young Carers	South Lanarkshire
Stirling Carers Centre	Stirling
Carers of West Dunbartonshire	West Dunbartonshire
Y Sort It	West Dunbartonshire
Carers of West Lothian	West Lothian
Western Isles Young Carers	Western Isles



### 4. National Carer Organisations (NCOs)

National Carer Organisations (NCOs) work to ensure that carers are recognised, supported and valued in all areas of their lives. They promote the interests of carers nationally to government to raise awareness and influence policy to improve the lives of carers. They also partner more locally with a network of carer centres and organisations that provide support and information directly to unpaid carers to enable them to live fulfilled lives and access the information, support and funding that they need.

There are six National Carer Organisations operating in Scotland.

#### **Carers Scotland**

Carers Scotland, part of Carers UK, provides information and advice on caring, helps carers connect with each other, campaigns with carers for lasting change, and uses innovation to improve services. It also runs the Carer Positive scheme, which supports Scottish employers to be more carer friendly.

#### **Carers Trust Scotland**

Carers Trust Scotland works to transform the lives of unpaid carers. They partner with a network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes, raise awareness and influence policy.

#### **Coalition of Carers in Scotland**

The Coalition of Carers in Scotland promotes the voice of carers in the development of services, policy and legislation and to strengthen carers' rights in Scotland.

#### **MECOPP (Minority Ethnic Carers of Older People Project)**

By working in partnership with carers, voluntary organisation and statutory bodies, MECOPP actively seeks to challenge and dismantle barriers that deny Black and Minority Ethnic carers access to health, social work and other social care services in Edinburgh, the Lothians and further afield.

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## Shared Care Scotland

Shared Care Scotland aims to improve the quality and provision of short breaks in Scotland. They cover a wide range of activities from information services such as a directory, events and publications through to research and policy work.

## The Scottish Young Carers Services Alliance

The Scottish Young Carers Services Alliance (SYCSA) is funded by the Scottish Government and is an informal network of young carers services across Scotland hosted by Carers Trust Scotland.

## 5. Further information and resources

### The Carers (Scotland) Act 2016

The definition of a carer according to the Carers (Scotland) Act 2016 is 'someone who provides or intends to provide care for another person because of a long-term condition or disability'.

- You can be caring for someone for **any** number of hours
- You do **not** need to be living in the same house as the person you are caring for
- The person you are caring for does **not** need to be in receipt of a social care package
- You, as the carer, do **not** need to be in receipt of carers allowance

The Carers (Scotland) Act gives young and adult carers rights. It places a duty on all local authorities in Scotland to ensure carers can exercise their right to:

- Access information and advice
- Create a personalised support plan to identify what is important to them. If you are over 18, this is called an 'adult carer support plan'. If you are under the age of 18, or you are 18 and still at school, this is called a 'young carer statement'
- Access support if the needs identified in their plan meet the local eligibility criteria for carers
- Be involved in the care planning and assessment processes for the person they care for

You can find out more about your rights here: [the Carers Charter](#).

Contact your [local carer centre](#) to receive guidance on exercising your rights, practical support and advice.

Care Information Scotland have produced a useful resource on [what to expect from key rights under the Carers \(Scotland\) Act](#).

For more details on support available for carers in Scotland, visit [Care Information Scotland](#) or [NHS Inform, Support for Unpaid Carers](#).

# Information for unpaid carers and professionals



## **The Neurological Alliance of Scotland Self-Directed Support Fact Sheets**

We published three factsheets to help people with neurological conditions, and their carers, access personalised support:

- [Self Directed Support for Adults: Information for Health and Social Care Professionals](#)
- [Self Directed Support for Adults: Information for the Voluntary Sector](#)
- [Self Directed Support for Children: What to Expect - Information for Parents](#)

## **The Neurological Alliance of Scotland 'What to Expect' Fact Sheets**

Guidance for people who care for those with neurological conditions:

- [What to expect when you are new to caring](#)
- [What to expect from advocacy services](#)
- [What to expect when planning ahead](#)

## **The Neurological Alliance of Scotland Neurological Conditions in the Community Leaflet**

In 2024 we published a leaflet to help adult social care professionals understand how best to support someone with a neurological condition/s.

## **Health Improvement Scotland General Standards for Neurological Care (2019)**

These are the most recent standards of care for neurology which aim to ensure consistency in the approach to neurological care and support services across Scotland. They are applicable to anyone living with a neurological condition in Scotland.

## **Care Information Scotland**

Care information Scotland provides information and advice for those who look after someone, need care themselves, or are planning for future care needs.

## **The Essential Advocacy Toolkit by Advocacy Focus**

Advocacy Focus supports people when they have health and social care issues and don't feel they are being heard or that their views are being respected. They created a co-produced advocacy toolkit with tips and ideas to help individuals speak up for themselves and start their self advocacy journey.

## **The Emergency Planning Toolkit by Enable Scotland**

This toolkit will help carers to create an emergency plan. Carers will be encouraged to answer the who, what, why, where, when and how of planning for those unforeseen circumstances.

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## 6. Directory of our charity members

An estimated one million people in Scotland live with a neurological condition that has a significant impact on their lives. This equates to 1 in 6 people.

The Neurological Alliance of Scotland is an umbrella body of organisations that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive.

For more information about the Neurological Alliance and the work that we do, visit our [website](http://www.scottishneurological.org.uk): [www.scottishneurological.org.uk](http://www.scottishneurological.org.uk)

Have you found this factsheet useful? **Tell us your views here**

Click on any of the logos below to take you to each charity's website.





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