

# **NEUROLOGICAL CONDITIONS IN SCOTLAND**

A guide for funders

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# CONTENTS

Introduction .....	3
Setting the scene .....	3
The purpose of this report .....	3
The landscape of neurological conditions in Scotland .....	4
Definitions and prevalence .....	4
Trends affecting neurological condition charities in Scotland .....	6
Priority needs .....	8
Priority needs of people with neurological conditions .....	8
Priority needs of carers .....	10
Prioritising needs at different ages .....	12
Priority solutions .....	14
Mapping solutions .....	14
Solutions that meet different needs .....	14
Solutions that involve campaigning, research, and work with frontline professionals .....	17
The role of charities and funders .....	18
Charities supporting people with neurological conditions .....	18
The role of charities .....	19
The role of independent funders .....	20
Conclusion .....	21
Key findings .....	21
Recommendations .....	21
Acknowledgements .....	22
References .....	23

# INTRODUCTION

## Setting the scene

One million people in Scotland live with neurological conditions. This number is set to increase as the population ages and medical advances enable people to live longer with multiple and complex needs. Neurological conditions affect people physically, making it harder for them to do everyday tasks. They also affect people cognitively and emotionally, making relationships more difficult, and they can shorten people's lives. Rapidly progressing conditions, such as motor neurone disease, can have a sudden and devastating impact. Lifelong conditions, such as cerebral palsy, can affect every aspect of a person's life from childhood through to adulthood.

Charities play a vital role in supporting people to understand their condition, manage their symptoms, and come to terms with their diagnosis. As the number of people with neurological conditions rises, charities and funders need to think more about where their support can be most helpful.

## The purpose of this report

This report is a guide for funders who want to support the neurological conditions sector in Scotland. There have been significant changes in the way the state funds health charities, so independent funders have a crucial role to play. By outlining the needs of people with neurological conditions, as well as the needs of their carers, their families and the charities that support them, this report equips independent funders with the information they need to work out how best to meet those needs. We do not focus on medical research into neurological conditions, although we do address research that relates to the care and well-being of those with neurological conditions. The report has the following aims:

- to explain the context of charities working in the neurological conditions sector;
- to outline the priority needs of people with neurological conditions, both condition-specific and spanning multiple conditions;
- to identify priority solutions to meet those needs; and
- to examine the role of independent funders in meeting those needs.

This report is the result of desk research and interviews with charities, funders and academics working on neurological condition issues in Scotland. We hope that the frameworks included will enable funders to think about how they can have a significant impact on the lives of those in Scotland living with these conditions.

# THE LANDSCAPE OF NEUROLOGICAL CONDITIONS IN SCOTLAND

## Definitions and prevalence

### Definitions

The World Health Organization's definition of neurological conditions is widely accepted within the sector:

*'Neurological disorders are diseases of the central and peripheral nervous system. In other words, the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles.'*

World Health Organization<sup>1</sup>

There is some debate about which conditions are included within this definition. Figure 1 shows some examples that are usually considered to be neurological conditions.

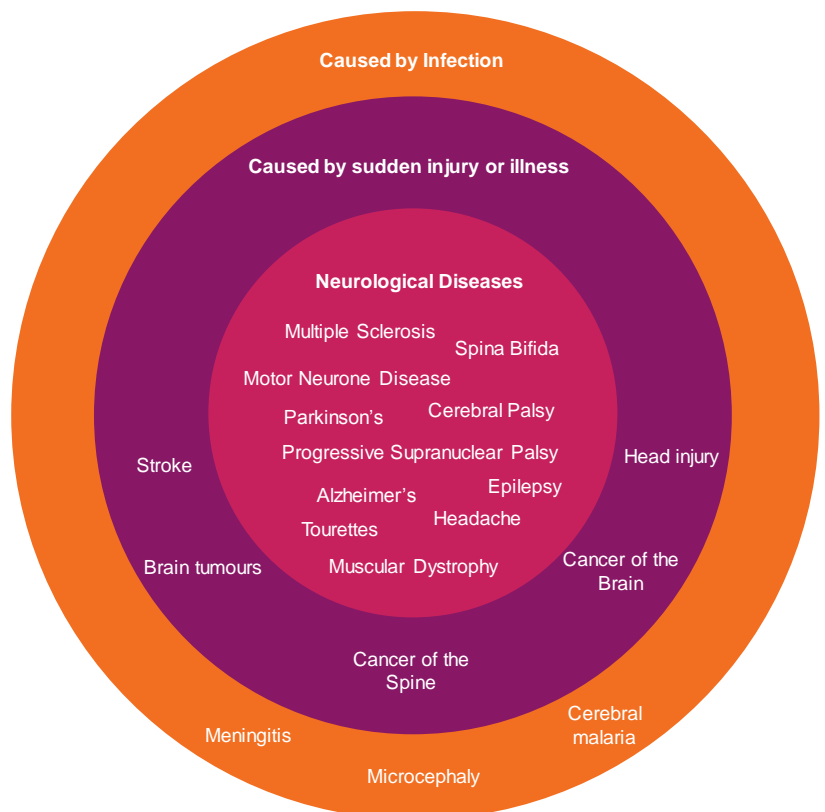
At the core of this diagram are **neurological diseases**, such as cerebral palsy and multiple sclerosis, which are always considered to be neurological conditions.

Around this are **conditions caused by sudden injury or illness**, such as stroke or cancer of the brain. From a medical perspective, these are neurological conditions. From a practical perspective, however, they are often grouped with other conditions. For example, brain cancer is usually grouped with other cancers as people tend to need cancer-specific treatment and support.

Similarly, **conditions caused by infection**, such as meningitis, are generally considered alongside other infectious diseases.

Some people experience neurological symptoms because their nervous system is not functioning properly, even though they do not have an underlying neurological disease. These **functional conditions**, such as non-epileptic seizures, account for around one in six patients seen by neurology services, but they are not included in most definitions of neurological conditions.<sup>2</sup>

Figure 1: Different types of neurological conditions



There are limitations in defining neurological conditions from a purely medical perspective. One interviewee pointed out that neurological conditions are viewed from a 'neurotypical' perspective. Conditions such as autism (which affects around 1 in 100 children<sup>3</sup>) challenge society to rethink what is considered 'typical'.

Medical definitions can also be problematic when it comes to learning disabilities, which, as one interviewee pointed out, have a complex relationship with neurological conditions. Learning disability is a descriptive concept, not a specific medical condition. The 'Keys to Life'—Scotland's learning disability strategy—defines people with learning disabilities as having '*a significant, lifelong condition that started before adulthood, which affected their development and which means they need help to understand information, learn skills and cope independently*'.<sup>4</sup>

Disability and learning disability charities often start with a social model, which says that a person is disabled because of how society is organised rather than due to their impairment or difference.<sup>5</sup> However, they acknowledge that learning disabilities may have a biological or neurological basis. Diagnosis of an individual's medical condition is often critical for them to receive the treatment and services that they need. Learning disabilities often exist alongside neurological conditions such as epilepsy and autism.

*'An individual starts life with a medical condition which results in a degree of cognitive impairment, but in the real world it is society's attitude to that condition which disables her or him, for example because it is assumed that she or he cannot work, have relationships and so on.'*

Chris Cregan, Scottish Commission for Learning Disability

## Prevalence

One million people live with neurological conditions in Scotland.<sup>6</sup> Many of these are people with headaches or functional conditions such as non-epileptic seizures.<sup>7</sup> Prevalence rates for individual conditions are hard to come by as records are not systematically gathered. Rates vary a lot between conditions, as Table 1 shows.

Table 1: Estimated numbers of people living with selected neurological conditions in Scotland

Condition	Number of people living with the condition in Scotland	Notes
Motor neurone disease	300	Estimate <sup>8</sup>
Huntington's disease	1,100	Estimate based on UK-wide figure <sup>9</sup>
Parkinson's disease	10,500	Estimate based on UK-wide figure. <sup>10</sup>
Multiple sclerosis	11,000	Estimate based on prevalence rate of 212 people per 100,000 in Scotland <sup>11</sup>
Cerebral palsy	15,000	Estimate <sup>12</sup>
Autistic spectrum disorder	50,000	Estimate for children and adults (although there are no prevalence studies for adults) <sup>13</sup>
Epilepsy	54,000	Estimate based on UK-wide figures. <sup>14</sup>
Dementia	90,000	Estimate of 2016 figures <sup>15</sup>

## Trends affecting neurological condition charities in Scotland

### Growing numbers

The number of people living with neurological conditions in Scotland is increasing, for several reasons. For example:

- As the population ages, more people are being diagnosed with age-related conditions such as dementia, motor neurone disease and Parkinson's disease.<sup>16</sup> The Scottish Government predicts that the number of people with dementia will double by 2035, affecting around 140,000 people.<sup>17</sup>
- Medical advances mean that people with neurological conditions are living longer with multiple and complex needs. The life expectancy for people with multiple sclerosis is only five to ten years lower than average life expectancy, and this gap is getting smaller all the time.<sup>18</sup>
- Premature babies are more likely to survive with conditions such as cerebral palsy, spina bifida and congenital hydrocephalus.

Scotland already has a relatively high number of neurological conditions. There is a particularly high prevalence of multiple sclerosis, which affects as many as 212 people per 100,000—one of the highest rates in the world—and the disease is much more prevalent in the north of Scotland than in the south.<sup>19</sup> The reasons for this may include genetic factors as well as environmental factors, such as a lack of vitamin D.<sup>20</sup> Huntington's disease is most prevalent in the north east of England and in Scotland according to a 2012 study, which shows a surprising doubling of prevalence from 1990 to 2010.<sup>21</sup>

### Services not keeping pace

Healthcare services are not keeping pace with these demographic changes. Neurological conditions account for one in five emergency hospital admissions and one in eight GP consultations in Scotland,<sup>22</sup> but these statutory services are overstretched and frontline professionals often have limited knowledge of neurological conditions. For example, people with cerebral palsy find that healthcare professionals do not understand how their condition changes as they age.<sup>23</sup>

Geographical factors also affect individuals' experiences of care. One expert told us about the stark contrast in service provision between two neighbouring local authorities—one has care managers for people with complex needs; the other has long waiting times to leave hospital, which has led to increased levels of disability. People living in more remote, rural areas of Scotland tend to have more limited service provision and are not always aware of what is available in other communities.

### Technological innovations

Technological innovations are helping to overcome inequalities in service provision for people with neurological conditions. For example, 14 teleneurology clinics across Scotland provide patients in remote or rural areas with access to specialist neurological services.<sup>24</sup> Charities like Sue Ryder are experimenting with virtual consultations enabled by cameras connected to patients' televisions.<sup>25</sup>

Handheld devices and wearable technology, such as Fitbits, can enable accurate monitoring of individual patients' symptoms. When data from lots of patients is aggregated, it can improve understanding of how to care for people with neurological conditions. As one interviewee expressed, *'there is massive untapped potential for patient-based studies'* which might lead to cohort-based personalised medicine in the future. The third sector is in a good position to design and pilot innovative services that make the most of technology.

## Waning policy interest

*'2010 marked the golden era [in policy interest] for neurological conditions. Since then, they have dropped off the agenda.'*

**John Eden, Scottish Huntington Association**

From 2005 to 2012 there was significant policy interest in improving neurological services in Scotland.<sup>26</sup> A review of neurological health services culminated in the publication of the NHS Clinical Standards for Neurological Health Services in 2009,<sup>27</sup> with a two-year programme to implement the standards across Scotland.<sup>28</sup> The Neurological Alliance of Scotland (the umbrella body for charities working in this field) influenced policy during this period.<sup>29</sup> Patients also participated in planning and improving local services through initiatives such as Neurological Voices.<sup>30</sup>

This momentum has slowed in recent years. The National Neurological Advisory Group (NNAG), which was set up in 2012 to oversee and support the work of NHS boards, did not achieve as much as many had hoped. One interviewee told us that health and social services were not sufficiently involved. Compounding these issues, the Scottish Government ended funding for the Neurological Alliance of Scotland in 2015. There is a sense from interviewees that the political agenda has moved on since the *'golden era for neurological conditions'* in 2010.

There are opportunities to put the spotlight back on improving neurological services. The NNAG was recently replaced by the National Advisory Committee for Neurological Conditions (NACNC), which is more focused on engaging with clinicians than its predecessor.<sup>31</sup> Healthcare Improvement Scotland is about to conduct a scoping exercise on the currency and relevance of the 2009 Clinical Standards.<sup>32</sup> Charities hope that these plans will include effective dialogue with the sector and a focus on person-centred approaches as well as clinical care.

## Changes to healthcare

Significant changes in general healthcare policy have affected the neurological conditions sector. Self-management has been at the heart of recent Scottish policy developments, with the aim of helping people living with long-term conditions to manage their own health and decisions about their care. The aspiration for greater patient control is a positive development, but there is little consensus on what it means in practical terms. Some interviewees worry that self-management is part of a government retreat away from providing healthcare services, with people expected to manage their own conditions even when this is not the most suitable option.

The Health and Social Care Integration agenda came into effect in April 2016, creating 31 local partnerships across Scotland, streamlining statutory services and collaborating with the voluntary sector. The experts we interviewed are concerned that the voluntary sector might be sidelined by the new Integration Joint Boards. One interviewee suggested the need for more concrete contractual relationships between the state and the third sector, rather than *'calling on the voluntary sector when they need to get out of a tricky situation'*.

# PRIORITY NEEDS

## Priority needs of people with neurological conditions

Although neurological conditions vary enormously, people with these conditions have many needs in common. In general, they want to understand their condition, remain as healthy as possible, and maximise their social, emotional and financial well-being (see Figure 2). Interventions in all of these areas are needed to support people to flourish and live their lives to the full.

Figure 2: Priority needs of people with neurological conditions



### Understanding their condition

Being diagnosed with a neurological condition can be a worrying time for individuals and their families. They need information and guidance to help them to understand their condition and understand how to access the services they need. Healthcare professionals are often not able to provide people with sufficient information due to a lack of time, resources, or even knowledge. This applies particularly to rarer conditions, such as motor neurone disease (MND). As one person diagnosed with the condition told researchers:

*'You go to your doctor and they have never had a patient with MND...the OT [occupational therapist] might have only ever seen one other person with it. So they have only got little tiny snippets of knowledge.'*

Sarah, quoted in Ferrie et al. (2015) *Living with MND*<sup>33</sup>



Experts we spoke with emphasised a lack of understanding of the *'hidden issues'* that people may not realise accompany a condition. These include cognitive and behavioural changes that are common to many neurological conditions. For example, one in three multiple sclerosis sufferers have some form of cognitive impairment.

People also need support to understand how to navigate statutory services. People with complex needs may find that they have dozens of different people treating different aspects of their illness. They want to be consulted, informed and involved in decisions about their health and their social care. Yet with inconsistencies between services and a lack of transparency about decisions, many feel excluded from the decision-making process.<sup>34</sup>

## Remaining healthy

People want to be as well as possible for as long as possible. Timely and accurate diagnosis needs to be followed up by appropriate treatment and care, including end of life care.



*'What people want is access to specialist knowledge about their particular neurological condition when they need it. Both patients and clinicians should be able to tap into specialist knowledge for support.'*

**Stephanie Fraser, Bobath Scotland Cerebral Palsy Therapy Centre**

Diagnosing a neurological condition is often a long and protracted process. It can be a distressing experience and can delay treatment. One study of people with MND, for example, found that 45% of patients waited more than 12 months for a diagnosis, and 19% waited more than 18 months.<sup>35</sup>

Many neurological conditions have no known cause, so there are very few treatments. However, specialist therapy and rehabilitation can help to reduce the deterioration of progressive conditions, alleviate symptoms, and improve people's quality of life. Interviewees told us that because of funding cuts and stricter eligibility criteria, it is increasingly difficult for people to access the services they need before crisis point. Poor coordination of services means that there can be long waiting times to leave hospital.

## Maintaining emotional well-being

People with neurological conditions commonly suffer from stress, anxiety and depression. The period after diagnosis is often a highly emotional time, and diagnosis with a severe and rapidly progressive condition is associated with *'emotional trauma'*.<sup>36</sup> The emotional and psychological adjustment to living with a neurological condition can involve deep changes to a person's identity, sense of self, and how they relate to others in their family and community.



Emotional issues can also be triggered directly by aspects of a neurological condition. People with multiple sclerosis, for example, can experience emotional changes as a result of nerve damage to certain areas of the brain or as side effects of some drugs used to treat multiple sclerosis symptoms.<sup>37</sup> The stresses and strain of common neurological symptoms such as pain, fatigue, disorientation, breathlessness and low energy are all potential triggers for anxiety and depression.<sup>38</sup>

It can be difficult to diagnose depression in people with neurological conditions because of the overlap with other symptoms. For example, people with Parkinson's disease typically display symptoms such as motor slowing, sleep and appetite disturbance, weight loss, loss of interest and concentration, and reduced libido—all symptoms associated with depression.<sup>39</sup> Subsequent changes in mood or behaviour that indicate a deterioration in emotional well-being may not therefore be picked up. Some people with neurological conditions—such as those with profound and multiple learning disabilities—cannot talk about their difficulties, so carers may overlook psychological and emotional problems.<sup>40</sup>

## Accessing social support

People with neurological conditions want to live life to the full, plan for the future, live as independently as possible, and enjoy social activities. But many find that their social life and family life suffers after they become unwell. They can feel isolated, and many need to access carers and support outside traditional working hours.



Those with physically limiting conditions can find it hard to leave the house or participate in sports and cultural activities. Some conditions, including multiple sclerosis and MND, are accompanied by communication difficulties, making it hard for people to interact. MND Scotland believes that communication is the highest area of unmet need among people with MND in Scotland.<sup>41</sup>

Other barriers to a fulfilling social life include activities not being adapted to people's needs and unhelpful attitudes from others. People with learning disabilities may need extra support to make friends and feel part of their local communities. Meanwhile, there are low levels of public awareness even about fairly common conditions such as epilepsy. And media coverage of some conditions, such as autism, can encourage stigma and reduce people to one-dimensional stereotypes.

## Being financially stable

People with neurological conditions face a range of financial burdens, and as a result, many suffer financially. For example, two thirds of families affected by Huntington's disease live on an income below the national average, and half of these families live below the poverty line.<sup>42</sup>



One reason for this financial strain is the extra costs associated with certain conditions. The extra costs of multiple sclerosis have been estimated at £200 per week, which includes costs associated with transport, health and personal care, food and drink, housing, fuel and power.<sup>43</sup> Another problem is that some people with learning disabilities and cognitive issues find it difficult to manage their money. One interviewee told us that *'it is not uncommon for people to be silently suffering around finance'*.

Many people are missing out financially as a result of problems accessing or retaining employment. Despite equality policies, people with neurological conditions often feel sidelined in the workplace, and people are often forced to give up their job even if they would like to continue working. For example, some employers are reluctant to adapt workplaces to make them accessible. People with genetic neurological conditions like Huntington's disease may even face discrimination when applying for positions with the armed forces and police.<sup>44</sup>

Recent welfare system changes have resulted in reduced incomes for those living with neurological conditions. For instance, some people have had particular benefits cut, some have been impeded by over-complicated forms, and others have been let down by welfare advisers who do not understand neurological conditions.<sup>45</sup> A recent survey found that 65% of people with multiple sclerosis in Scotland who receive disability benefits believe that they would be unable to afford essential items such as food and heating if their benefits were cut.<sup>46</sup>

## Priority needs of carers

Caring can be a positive and rewarding experience. However, the stresses and strains of caring for a loved one with a neurological condition can have negative repercussions. What is more, many people do not identify with the term 'carer' because they see their relationship as a relative, spouse or friend, to which caring activities are an integral dimension.<sup>47</sup>

Just like the people they are looking after, carers want to understand the condition and maintain their health, social life, emotional well-being, and financial situation.

## Understanding their situation

First and foremost, carers need support in *'understanding how to be a carer'*. After a loved one has been diagnosed with a neurological condition, carers and families need support to come to terms with the diagnosis, to understand and manage the symptoms, to understand medication and equipment, and to understand the practical, legal and financial implications for their lives. Interviewees emphasised the importance of carefully considered pathways to give carers the right information at the right time.

## Remaining healthy

Looking after someone with a neurological condition can be physically and emotionally exhausting. Carers' own health can suffer as they put the needs of their loved one ahead of their own needs. Over half of the people responding to a Carers UK survey indicated that they do less exercise since they started caring and 45% find it hard to maintain a balanced diet as a result of caring.<sup>48</sup>

## Maintaining emotional well-being

*'Some families would say they struggle, they fight—they use warlike language to describe what they do.'*

Jean MacLellan, The Autism Network Scotland

Having a family member with a neurological condition can be highly stressful for relatives and carers. They may struggle to come to terms with what it means for their future, or they may be impacted upon by aspects of some neurological conditions that affect the personality, behaviour and cognition of their family member. Huntington's disease, for example, commonly leads to mood and behaviour changes, which can put a strain on relationships.

Emotional needs vary depending on the carer's relationship with the person being cared for. For example, many older people with conditions like dementia or motor neurone disease are cared for by their spouses, and this can put marriages under significant strain.<sup>49</sup> Unsurprisingly, there is evidence that carers in more demanding situations are much more likely to suffer from lower emotional well-being.<sup>50</sup> Charities also highlight that support and advice needs to be readily available for children and young people whose parents or other relatives have been diagnosed with a neurological condition.

## Accessing social support

As their daily activities become dominated by looking after their loved one(s), carers can find that their lives are turned upside down. They are often unable to find time for social activities that they once enjoyed, and they may need to give up studies or work. In these circumstances, carers commonly experience *'a loss of personal freedom'*.<sup>51</sup> They may become increasingly isolated and lack social contact. As carers struggle to come to terms with their new life, they need strong social support networks and respite from caring.

## Being financially stable

Carers often face significant financial costs. If the person they are caring for has had to give up work, then they may have to provide financial support. Many carers remain in employment themselves, primarily as an economic necessity.<sup>52</sup> However, carers for people with neurological conditions are more likely than other carers to give up work due to the demanding nature of caring for someone with complex symptoms, especially for degenerative illnesses.

For those carers who are not in employment, carer's allowance is crucial to enable them to manage financially. Recent welfare reforms have caused alarm that loss of benefits may affect both the person with the neurological condition and his or her carer, leading to financial crisis for families.

## Prioritising needs at different ages

It is important to understand how a person's needs are affected by the age at which their condition is diagnosed and how those needs progress throughout their life. A child diagnosed with cerebral palsy at age three has different needs to an adult diagnosed with motor neurone disease at age 63, for example. Yet services often fail to understand the changing needs of people with neurological conditions.

*'[Services] for disabled people were not designed to address issues of ageing—and so when disabled people are “in transition” from one age to another cracks both within and across services become evident.'*

Paterson and Watson, *Ageing with a lifelong condition*<sup>53</sup>

Here we outline the priority needs for people in childhood, mid-life and older adulthood.

### Childhood



Early diagnosis and early intervention are critical for children with neurological conditions and children at genetic risk of developing a neurological condition. Support with developmental issues (such as communication and language skills) can help children with conditions including autism, cerebral palsy or learning difficulties to keep up with their peers. Despite compelling evidence of the impact of early diagnosis and treatment, many conditions are not being picked up early enough. Childhood neurological conditions are relatively rare and frontline staff may not be familiar with their symptoms. Charities are concerned that these conditions receive insufficient attention. Often it is quicker for a child to be diagnosed with autism if the child is already *'in the system'* with another condition such as a learning disability or epilepsy.<sup>54</sup>

*'Neurological conditions are often considered an ageing concern and paediatrics are given less attention.'*

Andy Wynd, Spina Bifida Hydrocephalus Scotland

A growing body of research is focusing on how the needs of children and young people with neurological conditions change as they age. In many cases, the condition itself is non-progressive, but it affects other aspects of health in a progressive way. For example, children with hydrocephalus often experience the early onset of puberty as their condition interacts with hormonal changes in adolescence.<sup>55</sup>

Young people with neurological conditions are also subject to problems that affect young people more generally (such as concerns with physical appearance and friendships), but these are often exacerbated by their condition. Times of transition are particularly difficult, as they can be concerned about the level of support they will get from their new school.

## Mid-life



Being diagnosed with a neurological condition in mid-life can be devastating. Many people diagnosed as adults are in the middle of their career or have a young family. Their condition may lead to a changed lifestyle, reduced income, extra pressure on their family, and feelings of guilt.<sup>56</sup> People with genetic conditions face the added burden of telling their children that they too may be at risk. The Scottish Huntington's Association told us that '*not enough time is spent*' on working out how best to deliver the news to children that they are at risk and how to support their emotional needs.

Neurological conditions affecting people in mid-life are often progressive and require specialist treatment to slow down the impact of the disease. But people are often left to manage their own condition. One study found that only 36% of people with multiple sclerosis in Scotland can access disease modifying therapies—compared with 68% in Northern Ireland.<sup>57</sup> Sue Ryder estimates that around 250 younger adults in Scotland with conditions like severe multiple sclerosis, Parkinson's disease or sudden brain injury are being inappropriately placed into older people's care homes. These care homes not only lack specialist services and neurological expertise, but can also be demoralising places to live as a younger person.<sup>58</sup> Other people who need less intensive support find that they are not a priority for services. One interviewee told us: '*[Though] old age and early years intervention are talked about and funded a lot, there is an age gap in the middle where people are expected to self-manage.*'

## Older adulthood



Older adults diagnosed with neurological conditions can find their lives completely disrupted. They may have been looking forward to a life of retirement or looking after grandchildren. They may already live with other conditions and find it hard to cope with the impact of a neurological condition on top of other symptoms. For example, people with Down's Syndrome are at an increased risk of developing dementia. Rapidly progressive conditions such as Parkinson's disease or motor neurone disease (typically diagnosed when people are in their 50s, 60s or 70s) can have a sudden and devastating impact on people's lives with symptoms including muscle weakness, difficulties eating and speaking, breathlessness, and cognitive impairment.

People diagnosed with neurological conditions in older age typically find that they suffer from a number of conditions and have to access multiple support services. Frontline health workers may not take into account dementia when looking at other aspects of health. Charities working with people who have dementia highlight the need to join up services around people's needs to avoid crisis moments where people end up in hospital.

# PRIORITY SOLUTIONS

## Mapping solutions

Priority solutions are those that most effectively meet the needs of people with neurological conditions and their carers in the areas of understanding, health, emotional well-being, social needs and financial needs.

Interviewees emphasised the importance of solutions that are:

- **Person-centred:** The best services fit around the needs, strengths and aspirations of the individual and his or her life circumstances. This will vary greatly depending on the condition and the age of diagnosis. Charities and funders can use the age framework in the previous chapter to think about how people's circumstances change over their lifetime. They can also engage people directly in creating services and influencing policies so that they work better for them.
- **Social:** There is evidence that interventions with a social dimension are more likely to improve people's physical, emotional and social well-being. Health professionals can improve outcomes by taking time to create a sense of teamwork with the patient and his or her family.<sup>59</sup> Social and community involvement provide meaning, purpose and connection to people's lives.<sup>60</sup>
- **Balanced between condition-specific and generic (see Figure 3):** Many of the needs of people with neurological conditions can be met by integrated services that are not condition-specific. Respite services, breaks for carers, emotional support, benefits advice, and some health services can all be delivered by generic providers—as long as they have sufficient understanding of an individual's condition. But condition-specific provision is essential to help people to understand their condition and meet their specialist health needs.

Figure 3: Finding balanced solutions for different needs



## Solutions that meet different needs

### Needs of people living with a neurological condition

#### Understanding the condition

Priority solutions include the provision of specialist post-diagnosis support to understand the condition, support to navigate the system and understand rights, and decent signposting to services. For example, the PSP

Association's helpline offers help and advice to patients, carers and health and social care professionals in a way that relieves anxiety resulting from unfamiliarity or lack of experience of what is a rare disease.<sup>61</sup>

A common issue with information provision is that it can be fragmented, with different organisations providing different types of information that is relevant to the same individual. This is an area where there is scope for charities to work more closely with one another in order to improve the experience for beneficiaries. For example, The Multiple Sclerosis Society and Multiple Sclerosis Trust recently came together to develop a theory of change that maps information provision for people with MS.<sup>62</sup> This is a novel step towards unifying information provision for people with a specific condition. It has promise for making information provision much easier for individuals to navigate. Other condition-specific charities could benefit from taking a similar approach.

## Remaining healthy

Solutions to meet people's health needs include access to specialist multi-disciplinary care where required—particularly for those with complex needs or rarer conditions. For example, specialist care nurses play a vital role in caring and supporting people with motor neurone disease (MND).<sup>63</sup> In 2015, following a high-profile campaign, the Scottish Government committed to doubling the number of MND nurses, which was welcomed by many of our interviewees.

Some charities are using technology to provide specialist healthcare where it otherwise would not exist. For example, social care charity Quarriers has developed video conferencing clinics that provide specialist support for people with epilepsy and their carers who would otherwise have to travel up to 330 miles.<sup>64</sup> Remote physiological monitoring and home-based medical applications can help people who have mild to moderate needs (including those with dementia) to remain at home for longer and be as independent as possible.

Some people we spoke with pointed out that if too many services become too specialist, then there will be less access for people with other conditions. Many of the specialist nurses in Scotland cater for a limited number of conditions, and there is concern that not everyone with a neurological condition has access to the expertise provided by these nurses.<sup>65</sup>

Generalist services can meet some people's needs around rehabilitation, therapeutic care, management of symptoms, respite and palliative care. One example of effective provision for many different conditions is Leuchie House, which provides respite services. Until 2010, Leuchie House was run by the MS Society as a centre for people with multiple sclerosis and their families. When the MS Society withdrew from funding the facility, Leuchie House reopened as an independent charity serving people with a variety of conditions including multiple sclerosis, MND, Parkinson's disease, stroke, cerebral palsy and Huntington's disease.<sup>66</sup>

## Maintaining emotional well-being

Priority solutions that meet people's emotional needs include counselling and peer-to-peer support. For example, Alzheimer Scotland identified a need for people with dementia to have private time with a skilled worker to help them come to terms with their inner thoughts and feelings. To address this need, the charity launched the 'Let's Talk About It' programme, which provides dementia sufferers with an outreach worker to help alleviate the devastating feelings associated with their diagnosis. Alzheimer Scotland has also started an online conversation through its *Let's Talk about Dementia* blog, to share the work of its allied health professionals.<sup>67</sup>

Some of the most effective solutions involve collaborations between organisations to combine condition-specific expertise with experience in providing emotional support. For example, the Scottish Huntington's Association partners with Breathing Space Scotland (part of NHS 24) to train its helpline staff to support the mental health of people with Huntington's disease. Breathing Space staff are educated about Huntington's disease and know where to signpost people for condition-specific medical advice.<sup>68</sup>

Priority solutions can also focus on vulnerable ages such as adolescence. For example, Perth Autism Support runs a six-week programme of evening sessions called 'I Am Me', designed to help secondary students with autism understand what the condition means for them. The sessions cover topics such as exploring feelings and

managing difficult times. Young people are able to talk about issues they face at school and at home and develop practical strategies to lower their anxiety. Parents report that the course has helped their children's self-awareness, ability to discuss their feelings, self-esteem and confidence.<sup>69</sup>

## Accessing social support

Priority solutions that meet people's social needs include befriending, peer support groups, participation in the arts, and programmes to develop social skills as young people become adults.

Volunteer befriending schemes can be particularly important for conditions that have a social stigma attached to them. For example, Interest Link Borders runs a specialist learning disabilities befriending service, which has created over 650 befriending links since 2001. Evaluations have shown that the service improves people's confidence, self-esteem, well-being, communication skills and life skills.<sup>70</sup>

Peer support networks are particularly valuable for rare neurodegenerative conditions that have low community awareness, leading to stigma and isolation. For example, Parkinson's UK runs local groups offering friendship, support and social activities. Its groups in Lothian include popular singing groups, dance classes, art classes, and gentle exercise.<sup>71</sup>

Peer-to-peer support is also critical at particular times in people's lives, such as the transition to adulthood. For example, Aspire in Edinburgh supports young people with Asperger's Syndrome to develop social skills as they leave school and become adults. An evaluation of one of its programmes found that involving young adults (who had already made the transition) to share their experiences was particularly effective and helped young people to develop a sense of belonging.<sup>72</sup>

## Being financially stable

Priority solutions that meet people's financial needs include working with employers to recruit or retain people who have a neurological condition, providing financial advice or welfare advice, and running projects for young people who want to move from education to employment.

For example, Borders Green Team Enterprises is a social enterprise that provides employment and training for adults with learning disabilities in the Scottish Borders. Trainees are encouraged to work towards a recognised qualification and their personal action plans include regular reviews of progress. The scheme has links with local and national employers to provide routes into supported and independent work.<sup>73</sup>

Many charities have a dedicated financial or benefits adviser, and these advisers tend to provide similar information, albeit tailored to a particular condition. Indeed, many people with neurological conditions have similar financial needs. For example, benefits assessments do not always take into account the fluctuating nature of conditions like Parkinson's disease and multiple sclerosis.<sup>74</sup> There is potential for neurological condition charities to collaborate more and to work with charities such as Citizens Advice Scotland, which is experienced in supporting people with long-term conditions to access benefits and tax credits.

## Needs of carers

The most important services for carers help them to understand their role, connect them with other carers and families, and give them a break. Families are better able to cope with stress following diagnosis if they have good family cooperation, hobbies and interests, and formal or informal social support.<sup>75</sup> Charities such as Pamis work with carers and families to ensure that their basic needs are met while they are caring for their loved one.<sup>76</sup>

Charities are developing services that fit around carers and families' busy lives. For example, Scottish Autism's Right Click e-learning course helps parents of children with autism to understand their child's needs. It was developed after the charity found that many of its helpline calls were from people looking for generic information about autism. Right Click gives parents a flexible way of accessing in-depth information while retaining the 'human touch' associated with speaking to an adviser. It takes parents through a range of bespoke videos and



support materials, backed up by an adviser who makes an introductory phone call and is on hand for participants to email while they are logged into the site. The course aims to provide information in a reassuring way and help parents to feel confident in their ability to solve problems.<sup>77</sup> Based on the success of this model, Scottish Autism has recently launched a Right Click course focused on the needs of girls and women with autism.<sup>78</sup>

## Solutions that involve campaigning, research, and work with frontline professionals

Direct support for people with neurological conditions, their carers and their families can be complemented by solutions that indirectly affect them. Priority solutions include campaigning, research, and developing the skills of health and care professionals.

Charities are supporting their beneficiaries to get involved in campaigning for changes to policy and practice. For example, the MS Society has produced a guide for people to campaign for access to disease modifying therapies in Scotland.<sup>79</sup> Similarly, the National Autistic Society has a guide to help people to campaign for local changes.<sup>80</sup> Charities also campaign to raise public awareness, change attitudes, and open up wider conversations about neurological conditions. An example is Alzheimer Scotland's 'Let's Talk about Dementia' campaign.<sup>81</sup>

Condition-specific charities are also engaging with policymakers to improve policy and practice. For example, the Scottish Huntington's Association received a grant from the Scottish Government to develop a new national care framework for people with Huntington's disease. The charity is developing the framework in partnership with patients, carers and professionals, and it will be rolled out across Scotland to bring consistency to standards of care.<sup>82</sup>

Charities can also make a difference to people's lives by supporting research to improve treatment and care. Patients are at the centre of medical research, and often want to know how they can help in the discovery of new treatments. Charities can help to bring the patient voice into research design. For example, the MS Society enabled multiple sclerosis patients to work with the James Lind Alliance to establish ten research priorities.<sup>83</sup> MND Scotland is funding the Future MND project, which seeks to introduce a digital platform for gathering clinical data from large numbers of patients. The information collected will help researchers to assess individual patient's needs as well as audit delivery of care to drive up standards across Scotland. Ultimately, this will help position Scotland as an ideal site for treatment trials.<sup>84</sup> In fact, one interviewee argued that Scotland provides a ripe environment for medical innovation, with several research active universities and a relatively stable population.

Some neurological conditions charities are educating frontline staff in other sectors. For example, MND Scotland's clinical specialists provide expertise about a rare condition that many health professionals, such as GPs, have little experience in dealing with.<sup>85</sup> Alzheimer Scotland is working with the Scottish Government, the Convention of Scottish Local Authorities and Social Work Scotland to test the impact of a dementia practice coordinator.<sup>86</sup>

# THE ROLE OF CHARITIES AND FUNDERS

## Charities supporting people with neurological conditions

Most charities helping people with neurological conditions in Scotland are condition-specific. In fact, fewer than 20 charities classify themselves as being a neurological conditions charity, and of these, just less than half have an income of less than £5,000.\* Condition-specific provision varies in scale, although the number of these charities roughly correlates with how rare the condition is. There are 34 autism charities and 20 multiple sclerosis charities, while there are fewer than ten charities dedicated to rarer conditions like Huntington's disease (see Table 2).

Table 2: Estimated number of charities per condition†

Condition	Number of charities in Scotland
Huntington's disease	2
Motor neurone disease	4
Cerebral palsy	4
Parkinson's disease	6
Epilepsy	8
Multiple sclerosis	20
Dementia	31
Autistic spectrum disorder	34

Most charities in this sector are small and medium sized, and just a few are very large. Around a third of the Neurological Alliance of Scotland's 37 member organisations have an income of over £1m. Most of the large charities are condition-specific—for example, Bobath Scotland supports children and adults who have cerebral palsy. Some (such as Capability Scotland) only work in Scotland; others (such as Parkinson's Scotland and MS Society Scotland) are Scottish branches of UK-wide charities.

Beyond the large well-known charities there are dozens of medium sized charities with an income between £100,000 and £1m. For example, The Haven in Lanarkshire helps people with life limiting conditions (including multiple sclerosis, motor neurone disease, Parkinson's disease and cancer) and their carers, through support groups, advice services and arts and crafts activities.

There are a host of small charities and community organisations with an income of under £100,000 in the sector, mostly targeted at a specific geographical area or condition. For example, Tourette Scotland provides information, advice and support for people affected by Tourette Syndrome, professionals and the public.

Many charities do not specialise in neurological conditions, but provide services to people with such conditions as part of their broader remit. Approximately 4,000 charities in Scotland serve people with disabilities and health

\* Office of the Scottish Charity Regulator, key word search: 'neurological' with the following filters—Constitutional form: all, Geographical spread: all, Charity type: all, Beneficiaries: people with disabilities or health problems, Activities: it carries out the services itself.

† Office of the Scottish Charity Regulator, key word search: of each condition name with the following filters—Constitutional form: all, Geographical spread: all, Charity type: all, Beneficiaries: people with disabilities or health problems, Activities: it carries out the services itself. Excluding charities without recent accounts or that work abroad.

problems, and many of these support people with neurological conditions.<sup>‡</sup> Some non-health charities also provide relevant services, for instance, by offering financial advice or emotional support.

## The role of charities

As well as working directly with people who have neurological conditions, charities support the people around them and strengthen the systems that affect them. Figure 4 shows the key roles that charities play.

Figure 4: How charities support people with neurological conditions



The independence, credibility and reach that charities have within communities make them uniquely placed to provide person-centred services that complement statutory services.<sup>88</sup> This is crucial for maximising people’s quality of life, supporting self-management, and reducing unnecessary hospital admissions.<sup>89</sup>

Condition-specific charities have a particularly important role to play. They are widely recognised as experts in managing the varied and complex needs arising from a neurological condition.<sup>90</sup> This makes them well-qualified to provide guidance to other voluntary and statutory organisations on how to tailor their services to people affected by neurological conditions. The box to the right shows the kind of factors that non-specialists may not be aware of.

Factors to consider in delivering services:

- Cognitive, psychological and physical impact of condition
- Additional complex health needs
- Diagnosis may be protracted or may remain unclear
- Conditions are often progressive
- Attendance variable due to health status
- Patients may require support person to attend

Adapted from Neurological Alliance of Scotland (2014) *Neurological Voices: Project Report 2011–2014*<sup>87</sup>

Charities that are not focused solely on neurological conditions bring their own specialist knowledge. For example, Samaritans staff and volunteers are experts in alleviating emotional distress and preventing suicide. They received over a million contacts in Scotland between 2010 and 2014, some of which were from people with neurological conditions.<sup>91</sup>

<sup>‡</sup> Estimate based on data from the Office of the Scottish Charity Regulator. The advanced search carried out consisted of the following—Beneficiaries: people with disabilities or health problems; Activities: it carries out the activities itself; Variant: geographical location.

## The role of independent funders

Besides the RS Macdonald Charitable Trust, very few Scottish foundations focus explicitly on neurological conditions. The Pixel Fund is a foundation that provides grants to charities involved in research and care in the fields of psychological, mental and neurological diseases and disorders. It funds across the UK and has funded Scottish projects including Alzheimer Scotland's 'Let's Talk about It' service.<sup>92</sup>

There are funders focusing on specific conditions, such as the Life Changes Trust's dementia programme, The Baily Thomas Charitable Fund's support for research into learning disabilities, and the Scottish Government's support for learning disability innovation projects through 'The Keys to Life' development fund.

There are of course many trusts and foundations funding health, well-being and inclusion projects, which can include charities working on neurological conditions. 13 of the 26 members of the Scottish Grant-Making Trusts Group (Scottish Grant-makers) appear to have relevance to a neurological conditions charity. The Robertson Trust funds services for people with dementia, Parkinson's, multiple sclerosis and other long-term conditions under the 'Care and Wellbeing' strand of its 2016-19 Giving Strategy.<sup>93</sup>

Independent funders can make a significant difference by providing long-term funding and paying for charities' core staff costs. Charities told us that grants like these allow them to *'think strategically'* and to retain specialist staff beyond individual projects. This is particularly important as government funding tends to be short term and oversubscribed. As one interviewee put it, funding for core running costs allows charities to provide the *'momentum for change'*, which is needed to improve the lives of people with neurological conditions.

*'It takes years to find, recruit and train [clinical specialists] and the charity has to make a commitment to them, so we need [funding for] these long-term core costs.'*

Stephanie Fraser, Bobath Scotland

Charities are keen to see funders acting more ambitiously to help people with neurological conditions. They are looking for a *'recognition of the urgency and immediacy'* of the issues and for funders to be willing to fund the *'radical solutions'* that are needed. Independent funders can invest in developing and piloting services to meet rising levels of need. They can also support preventative work to avoid crises, such as emergency hospital admissions.

The experts we interviewed told us that funders can act as a *'catalyst to get charities to work together'*. Charities can find it hard to collaborate when they are dealing with the day-to-day demands on their services amid a lack of resources. With various charities applying for the same pots of money, funders have a role to play in seeing the bigger picture and allocating resources where they are most needed.

Our interviewees were concerned that funders' cumbersome bureaucracy and rigid processes could get in the way of supporting innovation. An expert from one charity told us that she would love to see a situation where *'we are able to talk to folk with a pot of money about a problem'* and have that funder act on it. This would enable a more rapid response to the issues facing people with neurological conditions.

# CONCLUSION

People with neurological conditions want to understand their condition and live their lives to the full. But services are overstretched and frontline professionals often have limited knowledge of neurological conditions. The situation is getting worse as the number of people living with neurological conditions is increasing and services are failing to keep pace. Charities play a vital role both in directly supporting people with neurological conditions and in influencing the services that affect their lives.

## Key findings

We have explored the landscape of charities working on neurological conditions in Scotland, and discussed priority needs and solutions for people with these conditions and their carers. In summary, our findings are:

- The needs of people with neurological conditions vary widely depending on the age at which the condition appears. Solutions should take into account a detailed understanding of these distinct needs. Priority solutions include:
  - early diagnosis and access to specialist treatment for conditions that start in childhood;
  - treatment to slow down progression of diseases that are diagnosed in adulthood;
  - emotional support to help patients and their families come to terms with a diagnosis;
  - support to help people understand how their condition interacts with ageing; and
  - social activities and peer networks to tackle loneliness and isolation.
- Some of these needs are met by statutory services but others are not. Independent funders can add value by funding services that complement statutory provision and maximise people's quality of life.
- Projects that strengthen other services can have a huge impact on the well-being of people with neurological conditions and their carers. These include interventions to train frontline workers, research to improve treatment and care, and campaigning to influence policymakers and the general public.
- Neurological conditions are not generally considered together. Individuals usually seek out condition-specific advice and receive condition-specific support. Charities tend to work on individual conditions and advocate for the needs of their beneficiaries. There is potential for condition-specific charities to provide more effective services by collaborating, while keeping specialist services for where they are most needed.

## Recommendations

We have three recommendations:

- Funders should fund interventions that meet the needs of people with neurological conditions at different times in their lives.
- Funders should catalyse collaboration between charities to help provide more effective services and keep specialist services for where they are most needed. Long-term funding of core costs can help charities to think through these strategic decisions.
- The solutions that have the greatest impact on people's lives may not be frontline services. Funders should consider funding campaigning, research and training for other professionals.

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- <sup>89</sup> Neurological Alliance of Scotland (2015) *A review of the evidence around third sector's support to older people with degenerative neurological conditions in Lothian*, p.6.
- <sup>90</sup> Neurological Alliance of Scotland (2015) *A review of the evidence around third sector's support to older people with degenerative neurological conditions in Lothian*, p.19.
- <sup>91</sup> Samaritans website: [www.samaritans.org/your-community/samaritans-work-scotland](http://www.samaritans.org/your-community/samaritans-work-scotland)
- <sup>92</sup> The Pixel Fund website: [www.pixelfund.org.uk](http://www.pixelfund.org.uk)
- <sup>93</sup> The Robertson Trust (2016) *Giving Strategy 2016-2019*, p.5.

## TRANSFORMING THE CHARITY SECTOR

NPC is a charity think tank and consultancy which occupies a unique position at the nexus between charities and funders, helping them achieve the greatest impact. We are driven by the values and mission of the charity sector, to which we bring the rigour, clarity and analysis needed to better achieve the outcomes we all seek. We also share the motivations and passion of funders, to which we bring our expertise, experience and track record of success.

**Increasing the impact of charities:** NPC exists to make charities and social enterprises more successful in achieving their missions. Through rigorous analysis, practical advice and innovative thinking, we make charities' money and energy go further, and help them to achieve the greatest impact.

**Increasing the impact of funders:** NPC's role is to make funders more successful too. We share the passion funders have for helping charities and changing people's lives. We understand their motivations and their objectives, and we know that giving is more rewarding if it achieves the greatest impact it can.

**Strengthening the partnership between charities and funders:** NPC's mission is also to bring the two sides of the funding equation together, improving understanding and enhancing their combined impact. We can help funders and those they fund to connect and transform the way they work together to achieve their vision.

**New Philanthropy Capital**

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