

# Get Loud for MS

Be an 'MS: Voice for Change' at Holyrood





**11,000+**

people in Scotland are affected by Multiple Sclerosis

**670**

people are newly diagnosed with the condition every year

For over 11,000 people in Scotland, living with multiple sclerosis (MS) is a daily reality. MS is an unpredictable and incurable condition that affects people's nervous systems. It can attack suddenly or progress steadily, bringing a range of symptoms which can include sight loss, incontinence, fatigue and mobility problems. No-one with MS can be sure when or how it will affect them next.

With devolved health and social care, and even more powers to come, Scotland is in a strong position to lead the way in MS provision. It is

essential that people living with MS have access to the right support at the right time, regardless of where in Scotland they live. Unfortunately, we know at the moment that this is far from the reality. Now more than ever we need Parliamentarians who will give MS a voice at Holyrood.

We are asking candidates to support their constituents who live with the daily reality of MS by pledging their support to our three key asks. Together we can make a real difference to the lives of people in Scotland living with MS.

## Three key asks

1. Care, support and treatment for people living with MS is person centred, consistent and based within the community
2. Voices of people living with MS are heard in the health and social care integration process
3. Newly devolved powers create an empowering and fairer landscape for people living with MS

People with MS often suffer from fatigue and mobility issues. Excessive travel can further exacerbate their condition, meaning they need more support, or have to take time off work.



## 1. Care, support and treatment for people living with MS is person-centred, consistent and based within the community

No matter where you live in Scotland you should have access to the same high level of health and social care support. Differences in provision of care and support have led to a postcode lottery and people miss out on the care and support they need to manage their condition.

As part of the 2020 vision we have seen a move towards more person-centred care in Scotland. We call for this to continue to develop in a meaningful, effective way. MS is a complex and fluctuating condition which differs greatly from person to person and day to day. Care and support services and structures must reflect this and give people access to the treatment which is right for them.

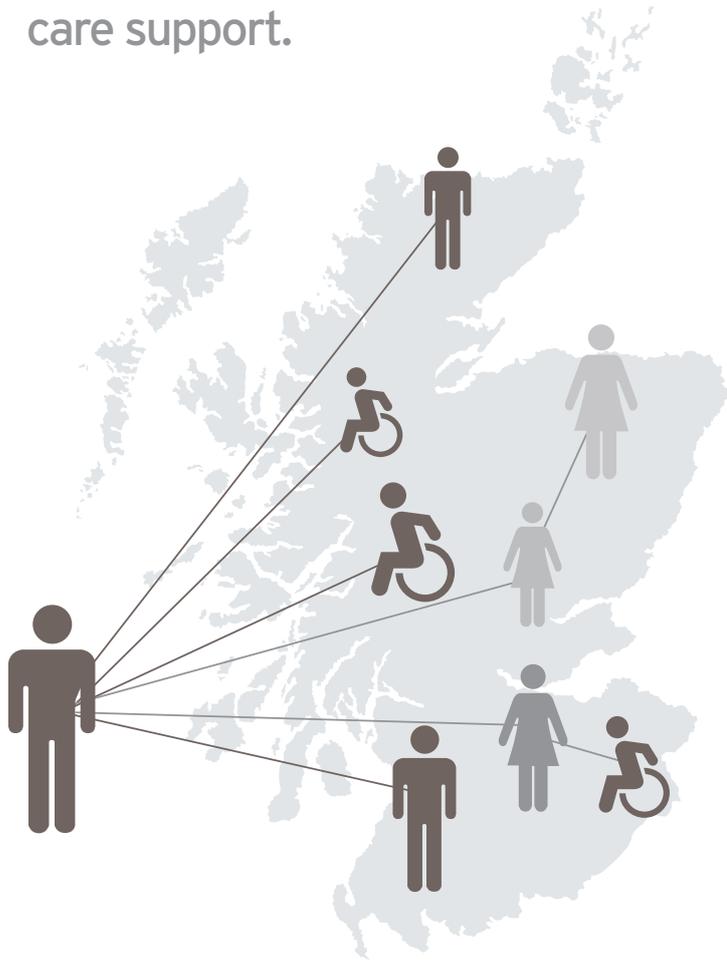
People with MS must also be supported to be active partners in managing their condition. We have been encouraged by action to promote self-management in Scotland. Our most recent figures suggest over 50% of people living with MS have

been offered an opportunity to attend a course on self-management, more than anywhere else in the UK. This is a promising start. We would support further extending access to self management courses to allow more people to manage their condition and maintain their independence.

In order for the right care and support to be accessible, it must be based within communities. This includes access to specialists, MS nurses, access to services or availability of therapies.

The geography of Scotland means that there is a relatively large rural population. This means that currently people can have to travel significant lengths to access the services they need to manage their condition. Some people travel in excess of 200miles for a one hour appointment. People with MS often suffer from fatigue and mobility issues. This excessive travel can further exacerbate their condition, meaning they need more support, or have to take time off work.

No matter where you live in Scotland, you should have access to the same high level of health and social care support.



“I feel completely abandoned by services. My neurological and rehab consultants are based in Aberdeen, and I haven’t seen either for many years because I can’t manage the 80-mile journey. If I have a question or a problem, there’s no-one I can talk to. I’m paying for physiotherapy myself, although I can’t really afford it, as I can’t speak to rehab services about accessing it through the NHS.

If all the services I needed were available nearer to where I live it would help me manage my MS better and greatly improve the quality of my life.”

**Lynn from Elgin**

## Take Action:

- Call for greater local service provision so that people don’t have to travel long distances to receive the care they need
- Hold health boards to account on their implementation plans for neurological service improvement
- Visit local MS branches and services in order to gain an understanding of the needs of people living with MS in your constituency.
- Champion the principles of person centred care and self management in the Scottish Parliament
- Recognise the important role the third sector can play in the design and delivery of services for the MS community

## 2. Voices of people living with MS are heard in the health and social care integration process

Health and social care integration has the potential to revolutionise the way care is designed and delivered in Scotland. The Scottish Government states that “...at its heart, health and social care integration is about ensuring that those who use services get the right care and support whatever their needs, at any point in their care journey“. However, it is vital that the voices of people who use services are heard throughout the process and that their views shape the services and support they receive. A recent Audit Scotland report re-iterated the point that the voices of service users and the third sector are vital to the success of health and social integration. Without these voices we will not hear the range of opinions needed to create a new way of working which puts the needs of the individual at the centre.

# 33%

didn't claim the benefits they were entitled to due to the public stigma .



"I have always received great support to help me manage my MS. In particular, my MS specialist nurse has been there to support me along the way. However, the services that are available to me aren't always the ones that I need. I would love a bigger voice in helping to design the services available to me. As people living with MS we are well placed to help shape services and make them relevant and worthwhile to the people accessing them"

**Charlie from Tayside**

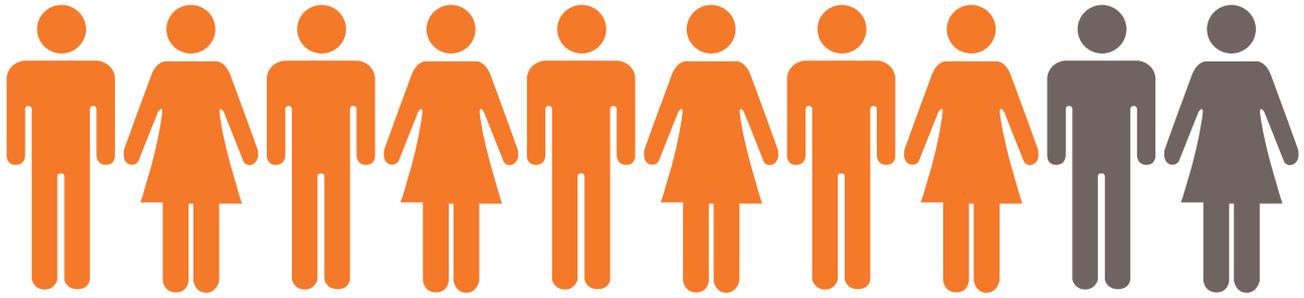
## Take Action:

- Champion the role of the third sector and people living with MS and other neurological conditions in health and social care integration
- Engage with health and care professionals in your constituency around the importance of user experience in service design and delivery
- Call for the implementation of Audit Scotland recommendations on health and social care integration

## 3. Newly devolved powers create an empowering and fairer landscape for people living with MS

The next Scottish Parliament will see the largest devolution of powers to Scotland since the Parliament's inception in 1999.

This provides Parliamentarians with a unique opportunity to use these new powers to create systems and processes which are open, accessible and empowering for people living with MS and other neurological conditions. In the first instance the devolution of aspects of welfare and the creation of a Scottish Social Security system provides an opportunity to change structures which have a particular impact on people living with long-term conditions.



**80%** of people with MS stop working within 15 years of the onset of their condition

Up to 80% of people with MS stop working within 15 years of the onset of their condition, whilst 70% agree their MS limits the range of jobs they can do. MS is a fluctuating and progressive condition, the symptoms of which are often hidden. This means that face to face assessments, like those used for Employment and Support Allowance (ESA) and Personal Independence Payments (PIP), can be problematic. As part of the MS: Enough campaign, the MS Society surveyed 1,780 people with MS on their experience of the disability benefits system.

Over half (57%) said that benefits assessments do not accurately reflect the impact of their MS. 50% of those who had a Work Capability Assessment (WCA) for ESA disagreed that hidden symptoms were considered.

Our campaign showed that 91% of people living with MS in Scotland found the process of claiming disability benefits stressful and that nearly 1 in 3 didn't claim the benefits they are entitled to due to the public stigma. The Scottish Parliament must do everything in its power to change this.

## Take Action:

- Support the MS: Enough campaign and calls to action
- Influence the creation of the Scottish Social Security system, so that it puts the needs of its users at the centre and recognises the nature of fluctuating long-term conditions such as MS
- Use new powers to create a more level playing field for people affected by MS. In particular consider how employability and social policy can be approached differently utilising the new powers

"I've had to battle to get the benefits I need. My last assessment for DLA caused me to have an anxiety attack: The assessor wasn't listening to me and his subsequent report was full of inaccuracies. Because of this, I'm dreading the day the brown envelope for my PIP assessment comes through the door. I hope that when the Scottish Government introduces a new Scottish social security system it will consider the needs of people living with neurological conditions like me and that they will create a compassionate and human rights focussed system. I want MSPs that will stand up for people living with long term conditions such as MS and help to make the systems they create as accessible as possible."

**Audrey from Inverness**



## Get Loud for MS

We need your support to ensure that the needs of people affected by MS are represented in the Scottish Parliament and within your party.

Please be a voice for change for the MS community. Show your support by using the #GetLoudForMS @MSSocietyScot or emailing [scotlandcampaigns@mssociety.org.uk](mailto:scotlandcampaigns@mssociety.org.uk).

### MS Society Scotland

[scotlandcampaigns@mssociety.org.uk](mailto:scotlandcampaigns@mssociety.org.uk)

T: 0131 335 4050

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

 /mssocietyscotland

 @mssocietyscot



## **MS National Centre**

372 Edgware Road  
London  
NW2 6ND  
Tel: 020 8438 0700

## **Wales**

MS Society Cymru  
Temple Court  
Cathedral Road  
Cardiff  
CF11 9HA  
Tel: 029 2078 6676

## **Scotland**

MS Society Scotland  
Ratho Park  
88 Glasgow road  
Ratho Station  
Newbridge  
EH28 8PP  
Tel: 0131 335 4050

## **Northern Ireland**

MS Society Northern Ireland  
The Resource Centre  
34 Annadale Avenue  
Belfast  
BT7 3JJ  
Tel: 028 9080 2802

## **MS Society National Helpline**

**Freephone 0808 800 8000**  
**Email: [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**  
**[www.mssociety.org.uk](http://www.mssociety.org.uk)**

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