

PRESS RELEASE

EMBARGOED UNTIL 8:00AM MONDAY 25 APRIL

## **NEW MS TRUST REPORT FINDS THAT PEOPLE WITH PROGRESSIVE MS 'FEEL LIKE THEY ARE GETTING A SECOND CLASS SERVICE'**

People with progressive MS make up around half of the UK's 100,000 MS population. But according to a new report published by national charity the MS Trust, growing pressures on NHS services mean they get much less support from specialist health professionals than people with relapsing remitting MS. As well as seeing health professionals less frequently, many people with progressive MS report being 'abandoned' by specialist services just as they enter the progressive phase of the disease, marked by complex symptoms and increasing disability.

The report **Is MS care fair?** is published on 25 April, to mark the start of **MS Awareness Week 2016**. The MS Trust surveyed over 1,800 people living with MS. They found that, while almost 80% of people with relapsing remitting MS had seen their neurologist and MS specialist nurse in the past year, around 40% of people with progressive MS hadn't seen either of these key health professionals. 12% of people with progressive MS reported receiving no specialist support at all in the last year.

Furthermore, 40% of people with secondary progressive MS, whose disease transitions from the relapsing form to the progressive, reported seeing less of their specialists once their disease became progressive. Many reported being effectively 'discharged' from the care of their neurologist and their MS specialist nurse and left to manage alone, with increasing disability and more complex symptoms. People with progressive MS may need to use a wheelchair or stay in bed, may require help eating, and may have severe cognitive difficulties and significant speech problems.

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Selected comments from survey respondents with secondary progressive MS:

- All of a sudden you get a feeling that you're no longer on the radar [of MS services] and that, in some respect, you've been abandoned by those that were previously involved with you.
- When I had relapsing remitting MS I was under the care of a neurologist and MS specialist nurse and took a DMD. Now that I am secondary progressive, I have been discharged from that care and referred to my GP – nothing else has been offered.
- There is no treatment for people with progressive MS, but little awareness that, because of this, we need **more**, not less, intervention from healthcare professionals.
- In my opinion once you are diagnosed with secondary progressive MS you are pretty much left to get on with it.

“These findings give us a vivid picture of how people with MS feel about the state of MS services today,” said Amy Bowen, Director of Service Development at the MS Trust. “They demonstrate the urgent need for new thinking to make MS care fair. We need to assess the challenges facing MS teams, including the impact of administering and monitoring disease modifying drugs, and develop new ways of delivering services that work for everyone living with MS, no matter what type of the disease they have.”

The MS Trust has launched a new campaign, **Let's make MS care fair** to highlight the pressures facing MS specialist services and the need for greater equity. It is has also begun work on a new one-year project, **MS Forward View**, working with clinicians, specialised and local commissioners, professional bodies, experts in service planning, multidisciplinary educators and people with MS, to produce an action plan to improve and measure access to care.

To find out more about the MS Trust's survey and its work to make MS care fair see <http://www.mstrust.org.uk/care>

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## Note to editor

If you would like a comment from the MS Trust or to speak to Amy Bowen, please contact Independent Media News on 0207 717 9696.

For more information about the work of the MS Trust, call Stephen Troussé on 01462 476734 or email [Stephen.trousse@mstrust.org.uk](mailto:Stephen.trousse@mstrust.org.uk)

## About MS

Multiple sclerosis is a condition that affects the nerves in the brain and spinal cord. It is a lifelong, condition, usually diagnosed in people's 20s and 30s, and can cause a wide variety of symptoms, including eyesight problems, fatigue, balance problems, altered sensations and cognitive issues. Over 100,000 people in the UK live with MS and it affects around three times as many women as men.

There are three main types of MS. 85% of people diagnosed have **relapsing remitting MS (RRMS)** at onset. When experiencing a relapse, people with MS can become very unwell for a period of days, weeks or months. They may recover completely, but around half of relapses leave some form of residual disability. Many people with relapsing remitting MS are treated with disease modifying drugs (DMDs). These are typically started soon after diagnosis to reduce the severity and frequency of relapses, and they may reduce disability.

Relapsing remitting MS may transition into **secondary progressive MS (SPMS)**, where there is a sustained increase of disability, independent of relapses. Around 58% of people with RRMS will develop SPMS 15–20 years after diagnosis.

10-15% of people with MS are diagnosed with **primary progressive MS (PPMS)**, where symptoms get progressively worse over time from the outset, rather than appearing as relapses. There are currently no disease modifying drugs that work in PPMS and none have any effect on the gradual accumulation of disability in SPMS. Those people who develop advanced MS may need to use a wheelchair or stay in bed, may require help eating, have severe cognitive difficulties and significant speech problems.

We estimate that current MS population of the UK comprises approximately 50% people with RRMS and 50% people with progressive forms of MS.

### **About the MS Trust**

The MS Trust is a charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We produce practical, reliable information, online and in print, and offer a telephone and email enquiry service to anyone who needs to know more about MS.

We work to make sure everyone affected by MS can access good quality, specialist care. We offer a full range of support to both specialists and health professionals with an interest in MS, including online information, publications, newsletters and professional development. We work in partnership with health professionals to improve MS services now and in the future.

For more information on the MS Trust's work see <http://www.mstrust.org.uk/>