

# Disability Insight

Take a look around you

**Multiple Sclerosis (MS) Awareness Day**

**27<sup>th</sup> Sept 2018**

## **Key points**

- Northern Ireland has one of the highest rates of MS in the world. It is estimated that there are around 4,500 people living with the condition.
- MS causes communication problems between brain and body that can lead to major damage to the nerves.
- MS symptoms overlap with those of other diseases and conditions often making it difficult to diagnose.
- It is estimated that over 50% of those diagnosed with MS are unemployed.
- Women are two to three times more likely to develop MS than men.

## **1 About MS**

Multiple sclerosis (MS) is a neurological condition, which means it affects your nerves. You get it when your immune system isn't working properly, and instead of fighting infection, the immune system attacks the nerves, and can stop or slow messages travelling along the nerve fibers. This can cause problems with memory, vision, balance, muscle control, as well as pain and fatigue. These symptoms vary from person to person. Although there is no cure for MS, there are treatments to help manage the condition.

There are 3 main types of Multiple Sclerosis:

### **Relapsing-Remitting:**

- This is the most common type of MS - about 85% of people diagnosed with MS have Relapsing-Remitting MS
- It is characterized by attacks (relapses) and remissions (recovery).
- Relapses tend to be unpredictable and their causes are unclear.

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**Primary Progressive:**

- Primary Progressive MS affects about 10-15% of people diagnosed with MS.
- People with Primary Progressive MS do not have distinct relapses and remissions, and symptoms gradually get worse over time.

**Secondary Progressive:**

- Secondary Progressive MS (SPMS) can develop following Relapsing Remitting MS, usually after a long number of years. With this type of MS, you're no longer likely to have relapses, and symptoms can get progressively worse.
- Around 40% of people develop Secondary Progressive MS.
- Research and the development of new drugs have meant that it takes longer to develop Secondary Progressive MS, and fewer people develop it.

**2 How does MS affect someone's life?**

MS can affect many aspects of a person's life. Symptoms are unpredictable and progression rates vary. People can also experience emotional and mental well-being difficulties and social and financial problems due to loss of earnings. Some of the most common symptoms include vision problems, tingling and numbness, pains and spasms, weakness and fatigue and balance problems or dizziness. Please click below links to read real life stories of people living with MS:

<https://www.belfasttelegraph.co.uk/life/features/two-brave-women-tell-us-about-living-with-multiple-sclerosis-31565430.html>

<https://www.mstrust.org.uk/news/views-and-comments/can%E2%80%99t-change-what-happens-just-have-deal-it-waynes-story>

Healthy eating, regular activity and exercise are important for both general health and fitness. Research has shown specific benefits of exercise for people with MS, including reduced fatigue and improved strength, mobility, and bowel and bladder function.

**3 Supporting someone with MS in work**

Work is important for well-being, income and to keep social contacts. There is a significant gap in employment rates between people with MS (36%) and the overall population (75%) in the UK, which means that people with MS may lose a significant number of working years. The current average employment rate of people with MS in the early stages is 37%, however this drops sharply for people with more advanced MS to just 4%. Prior to leaving work entirely, many people

with MS change their working pattern – 35% of people with MS work part-time, compared to the national average of 27%.

For many people with MS, having a supportive employer can enable them to manage their condition at work, and to remain in employment. There are many reasonable adjustments and types of support that can be offered to employees with MS. Some of the adjustments which have been put in place for people with MS include more breaks, somewhere to rest for short periods during the working day, a chair or stool to sit on, flexible and/or reduced working hours.

Because MS differs from person to person, and even on a day-to-day basis, the best way to find out what support your employee needs is by talking to them. Don't make assumptions about what your employee can and can't do. They may be able to continue doing their job as usual, without any additional support. If they do need additional support our Occupational Health Service or Employment Support Programmes, such as Access to Work may be able to help.

For further information on MS in the workplace please follow the below link:

<https://www.mssociety.org.uk/care-and-support/resources-and-publications/publications-search/ms-in-the-workplace-an-employers-guide>

#### **4 Support for you if you care for somebody with MS**

Caring for someone with MS can take its toll physically and emotionally; and juggling work and care can be challenging. The links below provide sources of support, as well as information on your statutory rights to help balance caring with work. Information on the different types of financial help that may be available to you is also provided below.

- [http://actionms.co.uk/downloads/Action\\_MS - MS & The Family.pdf](http://actionms.co.uk/downloads/Action_MS_-_MS_&_The_Family.pdf)
- <https://www.mstrust.org.uk/news/views-and-comments/10-ways-help-your-partner-if-they-have-ms>
- <https://www.mssociety.org.uk/care-and-support/support-for-carers>
- <https://www.carersuk.org/help-and-advice/work-and-career/other-rights-at-work>

#### **5 Support for you if you have MS**

MS is unique to each individual person, and severity and duration of symptoms can vary drastically. For this reason, there is no typical way to cope with MS. Understanding how MS affects your mind and body, and availing of services to

help build a supportive environment can be essential in helping you develop coping mechanisms for living with MS.

Initial diagnosis can be a very emotional period. Prior to diagnosis there can be a lot of frustration due to unexplainable symptoms. Once a diagnosis is confirmed, it can cause many emotions and feelings such as anger, shock, relief, and loss. The link below provides information and support if you have been newly diagnosed with MS:

<https://www.mstrust.org.uk/about-ms/newly-diagnosed/recently-diagnosed-ms>

Information on how to access support, including the MS Helpline and details of local support groups, are available by clicking on the links below. Information on the types of financial help you may be entitled to, as well as details on the availability of different disability benefits and grants, and how to access these is also provided.

- <https://www.mssociety.org.uk/care-and-support/emotional-support>
- <https://www.mssociety.org.uk/care-and-support/financial-help>
- <https://www.citizensadvice.org.uk/benefits/>
- <https://www.mssociety.org.uk/care-and-support/local-support>
- <https://www.mssociety.org.uk/contact-us/northern-ireland/resource-and-day-centre>

### Sources and further reading:

- <https://www.nhs.uk/conditions/multiple-sclerosis/living-with/>
- <http://actionms.co.uk/>
- <https://www.mssociety.org.uk/>
- <https://www.mstrust.org.uk/>
- <https://www.bbc.co.uk/news/uk-northern-ireland-39258041>

