



Multiple Sclerosis
New Zealand

About MS

Multiple Sclerosis (MS) is a chronic health condition, and the most disabling non-traumatic condition for young people globally. MS is a complex and unpredictable neurological condition that affects everyone differently. The official prevalence data revealed in 2006 there were 2917 people with MS (PwMS) in New Zealand. Latest estimates, based on more recent incidence and mortality data, suggest the number to have increased to around 4130 in 2021. Those diagnosed with MS in NZ range from teenagers to those in their 80s+ with the average age of diagnosis in NZ being in a person's mid 30s. This is a prime time of life for careers and families.

In MS, the protective myelin surrounding the nerves becomes damaged disrupting the signals that are sent from the brain to various parts of the body. The nerve transmission damage resulting from myelin sheath deterioration occurs in the central nervous system and is irreparable. This damage impacts cognition, vision, speech, swallowing, fatigue, movement, nerve sensations, the bladder and the bowel. Many of the symptoms are complex and unseen making the condition hard for many to understand. Mental health is a huge issue in the MS community impacted by many factors. The course of a person's condition and symptoms is relatively unknown and different for each individual. Because of this, MS is often referred to as the '**Snowflake Disease**'.

Each year approximately **134** New Zealanders will be **diagnosed**, and **94** people will experience their **first symptoms**, which might result in an MS diagnosis.

The prevalence of MS is disproportionately higher among females. Among the New Zealand population, 76% of people with MS were female (3,121), and the remainder were male (1,009). This pattern of higher prevalence among females is a global feature of MS.

We expect that the true numbers of people with MS, particularly for Māori, Pasifika and rural communities, are underrepresented due to access issues, complexities of the condition and a bias assuming MS is the most unlikely diagnosis.

MS has a significant impact not only on the person diagnosed but also partners, parents, families, whānau, children and employers. Children of parents with MS are hugely affected as symptoms can limit parents' abilities to be fully involved due to fatigue, pain, mobility and cognitive issues.

Living with a chronic, progressive condition MS is often isolating, scary, painful, exhausting and disabling. It is also expensive. There are often substantial extra costs, such as accessible transport, specialist equipment, medication and help with household activities. MS, if not well managed and supported, is also hugely disruptive to employment prospects, impacting individuals and families financial well-being and prospects.

People living with MS often have trouble with their mobility, require the use of mobility aids and experience other symptoms such as speech and cognitive difficulties, fatigue, muscle spasms and chronic pain. For those with restricted mobility, carrying out day-to-day activities can be extremely difficult and require significant support often provided by family and friends.

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Barriers identified by the MS community

People with MS experience barriers to access in many areas of their lives. Many of these barriers exist unnecessarily and inhibit the ability to participate fully in community life, live independently, access equitable services and healthcare and impact their physical health, mental health and well-being.

In July 2022 MSNZ ran a survey of people with progressed MS. Isolation and barriers to the community were identified as having a significant impact on their physical and mental health and well-being. We also receive regular reports from MS support workers in the community employed by our Regional Societies, highlighting access barriers being experienced by their members.

Particularly identified are:

- barriers to health care and community services and support;
- physical barriers limiting access and mobility;
- barriers to employment impacting their financial position;
- stigma, stereotyping and prejudice of people's perceptions or lack of knowledge;
- barriers to effective communication and information;
- social barriers enhancing isolation.

A particular issue of concern is the lack of residential care facilities for those needing it from a relatively young age. Nationwide people with MS, as young as in their 30s, are living in aged residential care. This lack of access to age appropriate care is completely unacceptable by every standard.

Effective legislation can look to address many of these issues and ensure people with disabilities, seen or unseen, to enable them to fully participate in their community.