

We need your help to support the 4000 people living with Multiple Sclerosis in New Zealand and their families



Recent overseas research shows that first world care for People with Multiple sclerosis (PwMS) requires four things which MS Organisations and key MS clinicians worldwide endorse¹²:

- 1) Early access to disease modifying treatment (DMTs) drugs to preserve brain and spinal cord tissue.
- 2) Early diagnosis and treatment is essential.
- 3) Regular monitoring of the disease and recording of this information formally are a key part of any successful management strategy.
- 4) Offering a full range of therapies can reduce disease activity and improve the chances of finding the best option for each person with MS.

New Zealand is not currently meeting these key recommendations. PwMS have a life-long chronic condition of the central nervous system, for which there is currently no known cause or cure, and need to be supported with integrated health, social and community services to best manage their condition, lead fulfilling lives and be positive members of the New Zealand community.

Currently PwMS in NZ experience:

- 1) Greater restrictions accessing DMTs than most other first world countries.
- 2) Long delays in new treatments being approved and funded in NZ.
- 3) Poor access or long delays in early diagnosis with specialist MS neurologists and key diagnostic testing such as MRIs required for treatment approval.
- 4) Poor or non-existent access to regular monitoring by neurologists, pain management specialists, rehab, continence, mental health or physio services. Annual reviews are only available for those on treatment.

What People with MS in NZ seek and deserve is:

- **Early diagnosis and treatment**

This is crucial for limiting and managing the irreversible, progressive deterioration. Currently access for specialist assessments, MRIs and other diagnostic and monitoring procedures are not provided in a timely manner by many DHBs.

PwMS often report symptoms of MS years before a diagnosis is made. Early symptoms are often misdiagnosed due to a lack of knowledge about the condition. Prioritising improved education among GPs and the public about the symptoms of MS alongside reducing referral waiting times will improve outcomes by enabling earlier diagnosis and access to treatment and support.

- **Guidelines for the minimum level of treatment and support provided for people living with multiple sclerosis**

There are no National guidelines for MS treatment which would ensure PwMS receive the same services, information and support wherever they live. Such guidelines are available in the UK and elsewhere in the world³. Every New Zealander should have the right to access a

¹ Giovannoni, G. *et al.* Brain Health: Time matters in multiple sclerosis (2017) www.msbrainhealth.org

² MS Ireland. Time to Act: A consensus on early treatment (2017)

³ National Institute for Health and Care Excellence. Multiple Sclerosis in Adults: Management. (2014) <https://www.nice.org.uk/guidance/cg186>

neurologist within one month of referral, an MRI following their first symptom presentation and an annual review for all those diagnosed, including an annual physiotherapy review. Regular monitoring is essential as the results of clinical examinations and brain scans will enable personalised treatment for every PwMS.

- ***Access to the best frontline treatments***

PHARMAC has funded some new MS treatments in recent years. However, the current funding criteria imposed by PHARMAC are more restrictive than overseas and not supported by current research. The criteria used exclude certain patients who clearly have MS, for whom access would have a profound effect in halting and preventing further disability. The funding criteria used (EDSS) solely accounts for ambulatory disability not other symptoms that are improved by treatment use including cognitive impairment and fatigue.

The funding applications are administratively onerous, taking up valuable neurologist and nursing time. MSNZ is in the process of advocating to PHARMAC to expand the access criteria and reduce the administrative burden.

- ***Access to specialists within a reasonable timeframe***

People with MS can wait many months to access new disease modifying treatments. Access to MS treatments requires a wide variety of tests. Referrals can take months depending on waiting lists. A recent OIA request to DHBs has shown that waiting times range between:

- Neurologist – 4 days to 4 months for a first appointment
- MRI – 2 weeks to 27.8 weeks based on priority
- Ophthalmologist – 24 hours to 4 months based on priority
- Physiotherapist – 4 hours to 5 months based on priority

Delays run the risk of people being unable to qualify for drug treatments by the time they are seen by a neurologist. Annual reviews must be completed on time or PwMS can be taken off treatment. Treatments reduce the risk of relapses and disability and are most effective if given early in the disease course.

- ***Integrated multidisciplinary care***

MS is a chronic condition that people can live with for 40 years or more. Over that time their needs change. Currently DHB services are not well integrated internally, nor do they work cohesively with services available in the community, including the Field Worker Service provided by MS Societies across the country.

- ***More MS neurologists and specialist MS nurses***

A New Zealand Medical Journal August 2015 article shows the NZ health system is already seriously short of neurologists and the position will only get worse with 50% of current neurologists due to turn 65 in the next 12 years. Currently only one new neurologist is entering the workforce each year. There are 34 FTE Neurologists in New Zealand when by international standards there should be 74.

- ***Residential care in appropriate facilities***

There is a lack of respite and long term residential care facilities for young people with MS. Young, mentally alert people with MS, because of their complex physical needs, can find themselves placed in the hospital wings of rest homes or in dementia care units with patients twice their age. This has been a long-term issue and there are still no solutions in sight.

- **Funding**

Funding for the charity sector is shrinking and funding for volunteer-based organisations that fulfil functions that should be funded by central government is increasingly difficult to come by. Grants to community groups are down 33% since 2004. 52% of current funding goes to sports. Between 1990 and 2005 the number of registered charities grew by 46%, in part due to the amount of available funding from Class 4 gambling.

In short, in New Zealand there is increased demand for services, reduced funding for the organisations and professionals that provide those services, resulting in 4000 people and their families living with a lifelong, progressive disease that is unpredictable and increasingly debilitating who aren't adequately supported.

What can you do to help?

We request:

- 1) Your support for increased funding to address critical staffing deficits in neurology services for specialists, such as neurologists and MS Nurses. Appropriate staffing numbers will ensure timely and equitable access to diagnosis and treatment.
- 2) Your commitment to address the lack of coordination of services within DHBs and between DHBs and primary and community services to best support those with long-term chronic conditions.
- 3) Your commitment to reviewing the funding of community organisations that are currently providing services that should be centrally funded.
- 4) Training and upskilling for General Practitioners on identifying early symptoms, treating and managing MS, so that GPs can play an integrated role in supporting people with MS to make informed decisions and provide care where no DMTs are available.
- 5) Development of nationally consistent guidelines to provide a pathway and expected level of care and service people with chronic conditions, such as MS.
- 6) Timely and equitable access to MRI scans and annual reviews so that, people with MS on treatment can access an MRI scan every year regardless of whether on treatment. Regular monitoring will allow for future planning based on an individual's recorded progression.
- 7) Support for a national patient registry, MS Base, to improve monitoring of the long-term effects of MS and the benefits of early treatment, and to allow for future planning of adequately resourced MS services.
- 8) Your commitment to addressing the need for greater access to residential care in appropriate facilities particularly for younger people living with chronic conditions.