

# Shocking: New Zealand death rate for motor neuron disease five times global average

 Glenda and Grant Lovatt. Grant has motor neurone disease and his wife cares for him full-time.

New Zealand's motor neurone disease death rate is the highest in the world and five times the global average, a new study has found.

Experts are warning this shocking new finding should be a major wake-up call for healthcare systems and research funding agencies to up their game.

The Global Burden of Disease (GBD) study - the world's largest scientific effort to quantify the health loss from more than 300 major diseases, injuries and risk factors - found the mortality rate for MND in New Zealand was as high as 2.2 deaths per 100,000 people.

Just ahead of Australia and the United Kingdom, and well above the global average of 0.46 deaths per 100,000 people.

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In New Zealand, the risk of developing the crippling condition - that takes away a person's ability to move, speak, swallow and breathe - was one in 300, and most died within 15 to 20 months of their diagnosis.

Sadly, the cause for the disease was yet to be discovered, which means the reason New Zealand was top of the chart was also unknown, Auckland University of Technology (AUT) professor and world-renowned neurologist Dr Valery Feigin said.

Feigin said the Government needed to take a better look at funding research priorities because neurological disorders were the leading cause of disability in the world and the burden was fast growing.

The significant shortage of neurologists in New Zealand was also likely to be a contributing factor that needed to be addressed as wait times for a patients with MND to get a consultation with a specialist was up to 15 months, Feigin said.

"The disease cannot be cured but an early diagnosis can help slow progression down."

A 2015 study estimated that with New Zealand's growing population, 77 neurologists were needed to meet patient demand.

Feigin said this was about three times the amount of neurologists that were already available.

Ian Powell, executive director of the Association of Salaried Medical Specialists, said overall New Zealand's specialist workforce for public hospitals was at a crisis and had been an ongoing problem.

"A shortage in neurologists would absolutely be the reason for the significant wait times."

Powell said this problem was continuing to get worse as the Government had not yet formed a coherent strategy to assess that workforce demand.

"These specialists were not only short but also weakened with a 50 per cent burnout rate."

Feigin said overall there needed to be more services available for people with motor neuron disease.

"Not only in terms of neurologists but also hospital beds, outpatient rehabilitation services and support systems."

With 3,600 collaborators in 145 countries, the GBD study has helped transform healthcare policy. It was co-ordinated by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington.

These findings come amid the Global Burden of Disease Brain Summit being held in Auckland this week with around 150 leading researchers from around the world attending.

Minister David Clark said the GBD study generated important insights into health and wellbeing at the global, regional, national and subnational levels.

"As such it is a valuable resource for health planning and care and is often used to inform strategic planning, priority setting, and also to help monitor progress along the way.

"I look forward to learning more about the GBD's most recent findings with regard to neurological conditions."

## Living with MND



Motor neurone disease has reduced sufferer Grant Lovatt and his wife Glenda to living off food parcels and they are on the verge of losing their house. Photo

/ Greg Bowker

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West Aucklander Grant Lovatt was dying of motor neurone disease and relied on his wife Glenda for full-time care.

He spends his days in an electric wheelchair with Glenda dressing, toileting, feeding and showering him.

The 58-year-old was diagnosed with MND in 2012 and in 2014 his neurologist gave him less than 12 months to live but he continues to battle through.

"Unfortunately, as of recent, he has gone downhill dramatically and he's starting to have a lot of trouble with his breathing and swallowing with extra saliva now - and he cannot do anything for himself at all anymore," Glenda said.

She said there was no treatment available other than palliative care which helped to make day-to-day life more comfortable.

"More funding for research on this horrible disease is so important - even help being able to better manage Grant's condition would be life-changing."

Both Glenda's uncle and auntie had died from MND but still she had so many unanswered questions.

## **Facts about Motor Neuron Disease**

- More than 800 New Zealanders are currently living with MND
- Each year around 120 people die from MND in New Zealand.
- The median age of onset of MND in New Zealand is 67 years.
- In New Zealand, 58 per cent of people with MND are male, and 42 per cent are female.
- Early symptoms are mild and may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles, and slurring of speech or swallowing difficulties due to weakness of the tongue and throat muscles.
- There is no cure for MND and the cause is unknown.