

# 'HOTSPOTS' HOLD KEY TO SURGE IN MND

Deaths triple in 40 years

PENNY TIMMS

Deaths from motor neurone disease have tripled in Australia in the past four decades, and scientists have now identified key regional “hotspots” where they say people are more likely to be struck down with the devastating neurological disorder.

“This is the first comprehensive look at national mortality from this deadly disease, and it shows MND is now responsible for one death in every 234 across the country,” says Carol Lee, of Macquarie University’s MND Research Centre.

Dr Lee is the lead author of an epidemiological review of Australian data, published in the Medical Journal of Australia.

“The national data points to a steady increase from 238 MND-related deaths in 1986 to 781 in 2023, with no obvious factor contributing to the growing mortality,” she said.

Where MND was responsible for around one in 500 deaths in 1986, researchers say that figure has grown significantly, accounting for one in 200 deaths in 2023.

MND is progressive and fatal, and there is no cure. In most cases, life expectancy is estimated to be between six months and three years.

Awareness of the disease has grown significantly in recent years due to

some high-profile patients, including AFL great and former Australian of the Year Neale Daniher and US actor Eric Dane, who died from amyotrophic lateral sclerosis, the most common form of MND, in February, aged 53.

As part of their analysis, researchers examined the locations of known patients in Australia and say their findings add weight to the theory MND has significant environmental or industrial links.

“We can show disproportionately that the death rate of this disease affects regional and rural populations more than urban populations,” neurologist Dominic Rowe said.

Professor Rowe is one of the report’s senior authors and has been focused on MND and movement disorders for the past 37 years.

“MND mortality in 2019-2023 was 1.4 times higher in Tasmania and 1.2 times higher in South Australia than in NSW, and significantly higher in regional areas compared to major cities,” he said.

The NSW Riverina is another region with high numbers, so too other parts of the state, according to Professor Rowe. He is part of a team examining limited existing data, though it is yet to be reviewed.

“In Orange in the last three years there have been 56 deaths from motor neurone disease. If there were 56 deaths from mesothelioma, there would be a taskforce assigned,” he said.

“About 10 per cent of MND is caused by faulty genes, but the vast majority is sporadic, and this is an environmental and we think perhaps even occupational disease.

“If I told you that 800 people were going to die from silicosis this year,

there'd be a national outcry. With 800 people dying with MND, people shrug their shoulders and say, 'oh well, that's bad luck'."

He says the evidence is similar to what is being seen in Parkinson's disease, which is another neurological movement disorder on the rise.

Where genetic factors were once believed to play a significant role in both, mounting statistics suggest other – likely preventable – causes play a far greater role.

The problem is that nobody knows exactly what the causes of MND are. Professor Rowe thinks it's time to change that so work can begin on preventing it.

To help, researchers want MND to be declared a notifiable disease and for a national database to be established to provide greater oversight of patient profiles and locations so new clues about the disease's causes could be identified.

"Nowhere in Australia do we systematically count who has MND," Professor Rowe said. "Until we understand who has it, where they are, where they live and what causes it, it's like going duck hunting at night with a blindfold on."

The research was funded by the NSW government.