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Motor Neuron Disease Mortality Trends in Australia From 1986 to 2023: A Population-Based Study

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ABSTRACT

Objectives: To analyse longitudinal change in motor neuron disease (MND) mortality in Australia from 1986 to 2023.

Design: Australian population-based study of MND mortality.

Setting: All MND mortality and Australian population data from 1 January 1986 to 31 December 2023 were obtained from the Australian Bureau of Statistics.

Main Outcome Measures: MND mortality records were analysed, and certified deaths were summarised by year of registration. MND mortality rates, 95% confidence intervals (CIs) and Joinpoint regression trends were calculated. Data were further subset by demographic and geographical categories to report Australian MND mortality by age group, sex, state/territory location and remoteness areas classification.

Results: In Australia, the total number of MND deaths more than tripled over the past 37 years, from 238 in 1986 to 781 in 2023. The unadjusted mortality rate in 1986 was 1.49 (95% CI, 1.30–1.69) per 100,000 population and increased to 2.93 (95% CI, 2.73–3.14) per 100,000 population by 2023. After age standardisation, the annual percentage change across 1986–2023 was determined to be 0.47% (95% confidence limit, 0.16–0.86). Joinpoint modelling suggests a more recent reduction in adjusted mortality rates. In 2023, MND accounted for 0.43% of all-cause deaths in Australia, increasing from 0.21% in 1986. The number of MND deaths in Australia peaked at age 70–79 years. MND mortality was higher among men than women (rate ratio, 1.41; 95% CI, 1.33–1.51). MND mortality rates were similar among New South Wales, Victoria and Queensland (2.93, 3.08 and 2.85 per 100,000 population, respectively), with higher rates in South Australia and Tasmania (3.44 and 4.12 per 100,000 population, respectively). MND mortality rates were higher in inner and outer regional areas (3.90 and 3.24 per 100,000 population, respectively) compared with major cities (2.79 per 100,000 population).

Conclusions: Adjusted MND mortality rates in Australia increased over 37 years.

JEL Classification: Nervous system diseases, Statistics, epidemiology and research design, Palliative care

Plain Language Summary

The known: Motor neuron disease (MND) leads to substantial global morbidity and mortality. There is a critical gap in epidemiological data on MND in Australia.

The new: Although classified as a rare disease in Australia, MND accounts for 1 in 234 deaths. In a concerning upward trend, MND deaths have tripled in 37 years. A new investigation into Australia-wide MND mortality found that it had doubled from 1986 to 2023.

The implications: Since mortality of a fatal disease is a proxy for incidence, these data highlight a sustained and unexplained rise in MND incidence in Australia.

1 | Introduction

Motor neuron disease (MND) is a fatal, progressive neurodegenerative disease that affects both upper and lower motor neurons. MND has a median survival of 27 months from diagnosis and less than 10% of patients with MND survive beyond 10 years [1]. Amyotrophic lateral sclerosis (ALS) is the most common subtype of MND, although most countries use both terms interchangeably [2]. In Australia, MND is arbitrarily classified as a rare disease, yet the Global Burden of Disease (GBD) study reported 39,081 MND deaths, ~268,673 prevalent cases of MND and 63,700 incident cases of MND worldwide in 2019 [3].

The absence of a compulsory national registry for MND in Australia limits comprehensive epidemiological assessments and accurate estimates of disease burden [4, 5]. This has resulted in limited epidemiological studies of MND in Australia. One state-based study reported the crude incidence rate of MND in South Australia was 3.34 per 100,000 population from 2017 to 2019 and the point prevalence was 6.79 per 100,000 population in 2019 [6]. Historical Australia-wide MND mortality studies reported a significant increase in MND deaths comparing the 1968–1977 period with the 1978–1987 period [7] and an increasing age-standardised death rate from the years 1971 to 2013 [8]. An updated nationwide analysis of MND mortality is warranted to identify epidemiological shift in patterns and geographical risk factors associated with the disease.

MND is commonly classified as either familial or sporadic, depending on whether there is clear inheritance of the disease within a family. Familial MND accounts for about 10% of cases, with more than 30 genes known to be associated with the disease [9]. The remaining 90% of patients with MND have no family history and are therefore classified as sporadic, although systematic genetic analysis of these patients identifies a genetic cause in a small proportion [10, 11]. There is evidence that sporadic MND may have environmental risk factors, including exposure to metals, pesticides, β-methylamino-$_L$-alanine, head injury and viral infections [10, 12–16]. An updated epidemiology for MND will support further studies to investigate geographical and environmental risk factors linked to sporadic MND.

Since MND is a universally fatal disease, mortality data reliably estimate incidence [17]. The objective for this study is to leverage Australia-wide MND mortality data to determine longitudinal change in the mortality and incidence of MND in Australia.

2 | Methods

The annual mortality data including the number of MND deaths and total all-cause deaths in Australia from 1 January 1986 to 31 December 2023 were obtained from the Australian Bureau of Statistics (ABS). The International Classification of Diseases (ICD)-10 code G12.2 (since 1997) and ICD-9 code 335.2 (before 1997) were used to define the cause of death due to MND. All doctor or coroner-certified deaths by year of registration were summarised in the ABS customised report. Subgroup data stratified by biological sex recorded on death certificates and provided by the ABS (total, men and women), age group (5-year groups, from 0–4 to ≥ 85 years), state and territory (only 5-year aggregated data for the Northern Territory and the Australian Capital Territory due to the confidentiality requirements associated with ABS data), and remoteness areas (1 January 2001 to 31 December 2023, data only available from 2001) were provided in this customised report.

The Australian population data based on estimated resident population by sex, age groups and state and territory were downloaded from the ABS Data Explorer datasets [18]. The population estimates by remoteness areas were downloaded from the ABS Data Cubes [19]. Data for remoteness areas were derived from the Accessibility/Remoteness Index of Australia Plus (ARIA+) and defined according to the Australian Statistical Geography Standard (ASGS) remoteness structure. Areas are categorised into five remoteness classes based on geographic access to services: major cities, inner regional, outer regional, remote Australia or very remote Australia [20].

Unadjusted mortality rates were based on the June quarter (Q2) estimated resident population of the reference year and expressed as deaths per 100,000 population. Unadjusted rates described by the Poisson distribution and the 95% confidence intervals (CIs) were calculated using Byar's method to provide accurate approximations to the exact Poisson probabilities. The potential years of life lost before age 75 years were calculated based on age at death estimated using the midpoint of the 5-year age group and represented in person-years. Rate ratios for comparison between variations were calculated with one category of each variable selected as a reference group. The 95% CIs were calculated using the Koopman asymptotic score method.

Statistical analyses for age standardisation and annual percentage change (APC) were performed with the Joinpoint Regression Program, Version 5.4.0.0 (April 2025; Statistical Research and Applications Branch, National Cancer Institute). Rates were age standardised to the Australian 2021 estimated resident population, and APC in rates and confidence limits (CL) were calculated using Joinpoint regression analysis. Age-adjusted mortality rates for MND from 1986 to 2023 were examined with Joinpoint regression to identify significant

changes in trends over time. Joinpoint regression applies Monte Carlo permutation tests to detect points where a significant change in trend occurs (termed joinpoints). The default maximum of seven joinpoints was allowed, with at least two data points between consecutive joinpoints. The APC for each segment between joinpoints was reported, and an APC $p < 0.05$ was considered statistically significant. Other statistical analyses were performed using GraphPad Prism version 10.4.2.

Findings were reported according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines (Table S1).

2.1 | Ethics Statement

This report uses data that are publicly available (CC-BY 4.0), that were accessed via a customised report request (cause of death due to MND and all-cause death) and by using the ABS's data extraction tool (Data Explorer), which allows the building of detailed customised data sets and is only accessible to those that enter into agreements with the ABS. Data sets can be recreated using the criteria outlined in the methods. The ABS is attributed as the source of data throughout this manuscript. As the study utilised publicly available and aggregated data, formal ethics approval was not required.

3 | Results

Between 1986 and 2023, a total of 19,935 deaths due to MND were registered in Australia. The number of MND deaths in Australia increased from 238 in 1986 to 781 in 2023 (Figure 1A, Table S2). The total number of MND deaths has steadily increased since 1986 in both men and women. The unadjusted mortality rate increased from 1.49 (95% CI, 1.30–1.69) per 100,000 population in 1986 to 2.93 (95% CI, 2.73–3.14) per 100,000 population by 2023 (Figure 1B, Table S2). After applying age standardisation, the age-adjusted mortality rate increased from 2.24 per 100,000 population in 1986 to 2.88 per 100,000 population in 2023 (Figure 1C, Table S3). Critically, MND deaths relative to all-cause deaths in Australia increased from 1 in 483 (0.21%) in 1986 to 1 in 234 (0.43%) in 2023 (Figure 2), which was evident for both sexes.

A higher MND mortality rate was estimated in men compared with women (Figure 1B,C), with a rate ratio of 1.41 (95% CI, 1.33–1.51) during the most recent period of 2019–2023 (Table 1). The highest number of MND deaths was among the 70–79 years age group (1367 deaths), while the highest mortality rate was evident in the ≥ 80 years age group at 16.1 (95% CI, 15.1–17.2) per 100,000 population (Table 1, Figure 3). Assuming the median age at death was 75 years, the potential years of life lost due to MND in 2023 were 4670 person-years, an increase from 2025 person-years in 1986.

From 1986 to 2023, the age-adjusted mortality rate increased at an estimated annual rate of 0.47% (95% CL, 0.16–0.86) before any modelling was applied (Figure S1A). The Joinpoint regression modelling analysis identified statistically significant Joinpoint, which divided the period into two distinct linear trend segments (1986–2009 and 2009–2023) (Figure S1B). The modelling output presented a preferred model: From 1986 to the Joinpoint, the age-adjusted mortality increased at an estimated annual rate of 1.54 (95% CL, 1.19–2.03). Since the 2009 Joinpoint, the age-adjusted mortality decreased at an estimated annual rate of −1.14 (95% CL, −1.86 to −0.58). Applying this sophisticated Joinpoint modelling, the overall increase in age-adjusted rates resulted from the preferred model across the entire period from 1986 to 2023 was 21.0%. This increase was calculated using the equation $[((1+0.0154)^{23}) \times ((1-0.0114)^{14})] - 1$, where between 1986 and 2009 (23 years), the age-adjusted rate increased by 42.1%; and from 2009 to 2023 (14 years), the age-adjusted rate decreased by 14.8%.

3.1 | State-Based Mortality

In a statewide comparison, the number of MND deaths in Australia were highest among the most populous states (Table 1, Figure 4A). In the period of 2019–2023, New South Wales, Victoria and Queensland recorded 1195, 1022 and 748 MND deaths, respectively. The corresponding mortality rates were 2.93 (95% CI, 2.77–3.10) per 100,000 population in New South Wales, 3.08 (95% CI, 2.90–3.28) per 100,000 population in Victoria and 2.85 (95% CI, 2.65–3.06) per 100,000 population in Queensland (Table 1). MND mortality rate during 2019–2023 was highest in Tasmania and South Australia and lowest in the Northern Territory. MND mortality in Tasmania and South Australia was 1.40 (95% CI, 1.16–1.70) and 1.17 (95% CI, 1.04–1.33) times that of New South Wales, respectively.

FIGURE 1 | (A) Number of deaths due to motor neuron disease in Australia by sex, 1986–2023. (B) Unadjusted mortality rate of motor neuron disease in Australia by sex, 1986–2023. (C) Age-adjusted mortality rate of motor neuron disease in Australia by sex, 1986–2023. Reference line indicates change in International Classification of Disease code [21]. Data Source: Based on Australian Bureau of Statistics Data.

FIGURE 2 | Total and sex-specific proportionate mortality of motor neuron disease, Australia, 1986–2023. Reference line indicates change in International Classification of Disease code. Data Source: Based on Australian Bureau of Statistics Data.

Conversely, MND mortality in the Northern Territory was 0.38 times (95% CI, 0.23–0.65) that of New South Wales (Table 1, Figure 4B).

3.2 | Mortality by Remoteness Areas

The ABS causes of death data for remoteness areas structure were defined by five classes of remoteness areas [20]. In 2019–2023, 67.2% of MND deaths were recorded in the major cities of Australia (2607 deaths) (Table 1). However, mortality rates were significantly higher in inner regional and outer regional areas, at 3.90 (95% CI, 3.65–4.17) and 3.24 (95% CI, 2.90–3.60) per 100,000 population, respectively, compared with 2.79 (95% CI, 2.68–2.89) per 100,000 population in major cities. In contrast, remote and very remote areas recorded significantly lower mortality rates of 1.73 (95% CI, 1.13–2.54) and 1.63 (95% CI, 0.93–2.64) per 100,000 population, respectively, compared with major cities (Table 1, Figure 5). In New South Wales and Victoria, the mortality rates of inner (3.70 [95% CI, 3.29–4.15] and 4.04 [95% CI, 3.55–4.58]) and outer (4.05 [95% CI, 3.20–5.06] and 4.60 [95% CI, 3.50–5.93]) regional areas were significantly higher than those in the major cities (2.66 [95% CI, 2.48–2.85] and 2.78 [95% CI, 2.58–2.99]). In Queensland, the mortality rates of the inner regional area (3.94 [95% CI, 3.42–4.53]) were significantly higher than those in the major cities (2.63 [95% CI, 2.39–2.88]) (Table S4).

4 | Discussion

Analysis of longitudinal, nationwide mortality data reveals a discernible rise in the burden of MND in Australia. Previous efforts to establish voluntary opt-in registries, such as the Australian MND Registry (AMNDR) and MiNDAUS, have not successfully captured the full extent and distribution of MND in Australia [4, 5]. In contrast, mortality data specifically identifying individuals who died of MND, either as direct or underlying cause of death, serves as a proxy indicator for MND incidence. Before this study, the Australian Institute of Health and Welfare (AIHW) released national electronic tabulations from the AIHW National Mortality Database, recording MND-related causes of death from 1959 to 2023 [22]. Our current study presents a more comprehensive analysis, including detailed demographic and geographic breakdowns of these data. Strikingly, MND has increased as a cause of death from 1 in 483 deaths to 1 in 234 deaths since 1986, with no clearly identified contributing factors.

In Australia, there has been a threefold increase in the number of MND deaths over the past 37 years. This is consistent with our previous study reporting a considerable increase in MND age-standardised death rate in Australia from 1971 to 2013 [8]. A rise in mortality due to MND has also been reported in other western countries. The age- and sex-standardised MND mortality rates in Norway increased from 1.3 per 100,000 population during the period 1951–1954 to 2.8 per 100,000 population in 2010–2014 [23]. A study in Denmark reported that the MND mortality rate increased fivefold from the period 1980–1981 to 2020–2021 [24]. The GBD study reported that the worldwide age-standardised mortality rates of MND have increased by 8% from 1990 to 2016 [25]. In the same study, the authors reported an increase of 21.9% in age-standardised mortality rates in Australia from 1990 to 2016 [25], whereas our study showed an increase of 28.6% in age-standardised mortality rates over a longer period from 1986 to 2023. Systematic identification of genetic forms of MND has not been routine practice in Australia. Since genetic MND accounts for only a small proportion of cases and genetic carriers are often asymptomatic, the increase in MND mortality

TABLE 1 | Number of motor neuron disease (MND) deaths, MND mortality rates and rate ratios presented in the 2019–2023 period.

All deaths	Number of MND deaths	Rate (95% CI)[a]	Rate ratio (95% CI)[b]
Year of death			
1989–1993	1566	1.82 (1.73–1.91)	0.60 (0.57–0.64)
1994–1998	1866	2.05 (1.96–2.14)	0.68 (0.65–0.72)
1999–2003	2394	2.49 (2.39–2.59)	0.83 (0.79–0.87)
2004–2008	2745	2.67 (2.58–2.78)	0.89 (0.85–0.93)
2009–2013	3316	2.96 (2.86–3.07)	0.99 (0.94–1.03)
2014–2018	3365	2.78 (2.69–2.88)	0.93 (0.88–0.97)
2019–2023	3887	3.01 (2.91–3.10)	1
Sex (2019–2023)			
Men	2263	3.53 (3.38–3.67)	1.41 (1.33–1.51)
Women	1624	2.49 (2.37–2.62)	1
Age group (2019–2023), years			
0–39	39	0.06 (0.04–0.08)	0.004 (0.003–0.006)
40–49	129	0.78 (0.65–0.92)	0.06 (0.05–0.07)
50–59	458	2.90 (2.64–3.18)	0.21 (0.19–0.23)
60–69	1025	7.47 (7.02–7.95)	0.53 (0.49–0.58)
70–79	1367	14.1 (13.3–14.8)	1
≥80	869	16.1 (15.1–17.2)	1.15 (1.05–1.25)
State/territory (2019–2023)			
New South Wales	1195	2.93 (2.77–3.10)	1
Victoria	1022	3.08 (2.90–3.28)	1.05 (0.97–1.14)
Queensland	748	2.85 (2.65–3.06)	0.97 (0.89–1.07)
South Australia	311	3.44 (3.07–3.85)	1.17 (1.04–1.33)
Western Australia	416	3.02 (2.73–3.32)	1.03 (0.92–1.15)
Tasmania	116	4.12 (3.40–4.94)	1.40 (1.16–1.70)
Northern Territory	14	1.12 (0.61–1.89)	0.38 (0.23–0.65)
Australian Capital Territory	64	2.84 (2.18–3.62)	0.97 (0.75–1.24)
Remoteness areas[c] (2019–2023)			
Major cities	2607	2.79 (2.68–2.89)	1
Inner regional	891	3.90 (3.65–4.17)	1.40 (1.30–1.51)
Outer regional	338	3.24 (2.90–3.60)	1.16 (1.04–1.30)
Remote	26	1.73 (1.13–2.54)	0.62 (0.42–0.91)
Very remote	16	1.63 (0.93–2.64)	0.58 (0.36–0.95)

Abbreviation: CI, confidence interval.
[a]Mortality rate per 100,000 population.
[b]Rate ratio compares to a reference group per category.
[c]Remoteness area defined by the Australian Statistical Geography Standard (ASGS), Edition 3 [20].
Data Source: Based on Australian Bureau of Statistics Data.

is more likely attributed to sporadic MND. This change, in addition to the marked difference in MND mortality by remoteness areas, suggests that environmental factors have a substantial role in the increasing number of MND-related deaths.

Our study employed a multidimensional approach to analyse longitudinal change in MND mortality in Australia. Between 1986 and 2023, a consistent increase in MND mortality was evident across multiple indicators, including absolute death

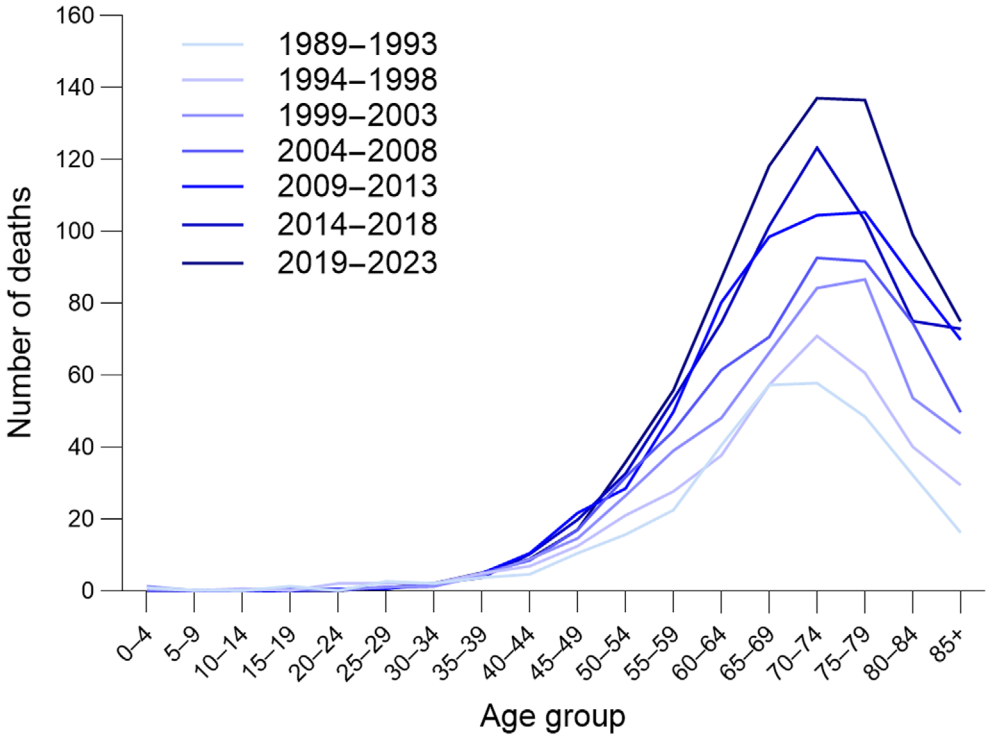

FIGURE 3 | Number of deaths due to motor neuron disease in Australia by 5-year age group, 1986–2023. Data Source: Based on Australian Bureau of Statistics Data.

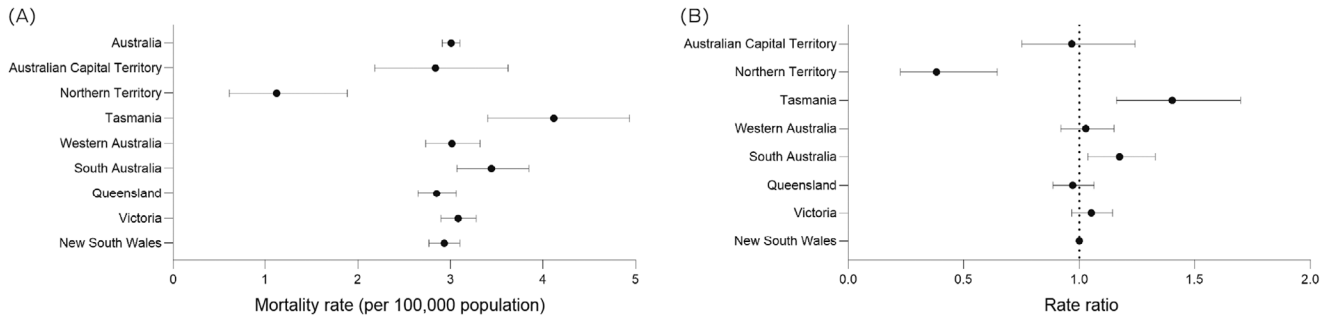

FIGURE 4 | Motor neuron disease mortality rate and rate ratios by states and territories in 2019–2023. Error bars show 95% confidence interval (CI). Rates, rate ratios and their 95% CIs are presented in Table 1. (A) Motor neuron disease mortality rate (B) Motor neuron disease mortality rate ratios. Data Source: Based on Australian Bureau of Statistics Data.

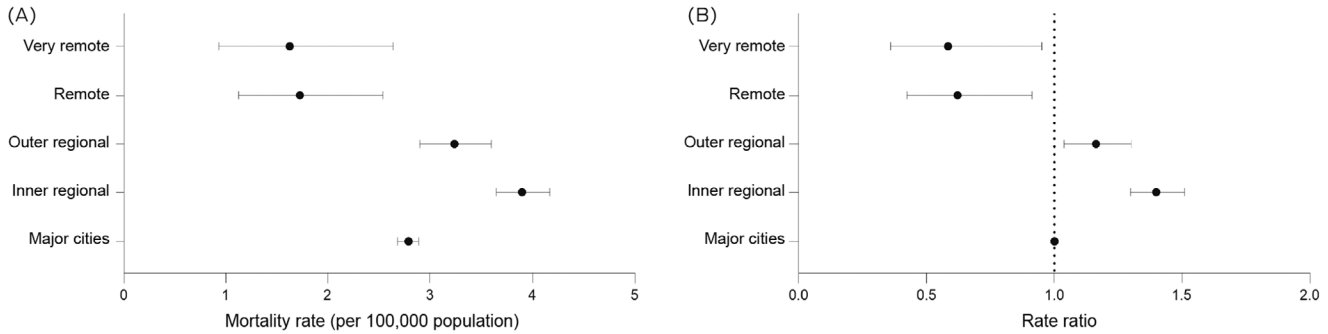

FIGURE 5 | Motor neuron disease mortality rate and rate ratios by remoteness areas in 2019–2023. Error bars show 95% confidence interval (CI). Rates, rate ratios and their 95% CIs presented in Table 1. Remoteness areas defined by the Australian Statistical Geography Standard (ASGS) Edition 3 [20]. (A) Motor neuron disease mortality rate (B) Motor neuron disease mortality rate ratios. Data Source: Based on Australian Bureau of Statistics Data.

counts, unadjusted and age-adjusted mortality rates, and proportionate mortality relative to all-cause mortality. Using advanced modelling techniques, we identified an overall 21.0% rise in age-adjusted mortality rates over the study period. Regression analysis revealed two distinct phases: a significant upward trend from 1986 to 2009, followed by a decline

from 2009 to 2023. The estimated post-2009 decrease warrants further investigation to elucidate potential underlying factors, which are likely to be environmental. Despite this recent decline, the overarching trend across the entire period indicates a sustained increase in MND mortality. The AIHW reports a 49% decline in the number of potential years of life lost per 1000 population between 1986 and 2023 [26], in direct contrast to our study, where we document a 44% increase in potential years of life lost due to MND for the same period. The demographic distribution of MND mortality in our data was consistent with reports from other western countries. There is a higher MND mortality rate in men compared with women [27], with the peak age at death occurring between 70 and 79 years [23, 24, 27]. The underlying reasons for this sex disparity remain unclear and warrant further investigation. Potential contributing factors such as occupational exposures, recreational activities or other environmental influences have been hypothesised but remain unconfirmed. Importantly, this pattern does not align with autosomal dominant inheritance, suggesting that genetic predisposition alone is insufficient to explain the observed difference.

South Australia had a higher prevalence and incidence of MND compared with the GBD global estimates [6]. In our study, we confirmed this result by also observing higher mortality rates in South Australia compared with other states. When considering potential environmental factors that may be causing this increase, Adelaide accounts for about 80% of South Australia's population and is near agricultural areas such as cropping and horticulture [28]. When we compared MND mortality rates across remoteness areas, our study identified significantly higher mortality rates in the inner and outer regional areas than the major cities—areas that are generally considered to have higher agricultural activities compared with major cities [28]. Various reports from the United States, Spain and Italy have shown an association between pesticides or occupation in agriculture with MND risk [12, 29–31]. This suggests a potential link between higher MND mortality rates and agricultural land use, warranting further investigation. Taken together, our finding of elevated MND mortality in regional areas compared with cities suggests that individuals residing in regional areas may be exposed to causal factors not encountered by their city-dwelling counterparts. We hypothesise that lifestyle and recreational activities, as well as environmental contaminants, could have a role in MND pathogenesis. However, this requires further investigation, and our ongoing work aims to explore this important aspect in greater depth, with a particular focus on regional areas. Our findings emphasise the need for a compulsory national registry of MND to facilitate systematic analysis of potential geographical and environmental risk factors for MND.

Globally, the prevalence and incidence of MND vary widely. Recent literature reported the global incidence rate of MND ranging from 0.3 to 23.5 per 100,000 person-years with a point prevalence ranging from 1.6 to 11.8 per 100,000 person-years [32, 33]. In 2021, the GBD study reported substantial regional variation in the age-standardised prevalence rate of MND, ranging from 1.11 to 1.70 per 100,000 population in sub-Saharan Africa, to 9.66, 9.23 and 9.00 per 100,000 population in Western Europe, North America and Australasia, respectively [34]. The highest age-standardised incidence rates were in Australasia, North America and Western Europe, with 2.6, 2.1 and 2.0 per 100,000 person-years, respectively [34]. The lowest age-standardised incidence rates were reported in sub-Saharan Africa, with 0.39 to 0.44 per 100,000 population [34]. The higher incidence and prevalence estimates for western countries align with our findings of a comparatively high MND mortality in Australia. This unexplained increase coincides with recent economic modelling by MND Australia, which estimated that the total economic cost and burden of disease associated with MND rose substantially, from $2.3 billion in 2015 to $5 billion in 2025 [35]. These parallel changes highlight the escalating health and economic impact of MND and underscore the need for further investigation into the underlying drivers of disease causation.

4.1 | Limitations

The ABS mortality data are comprehensive and include data for all states and territories across Australia over 35 years and more. However, data with small value in certain subgroups were randomly assigned to larger groups to protect the confidentiality of individuals. Data with very small values were presented in aggregated form, such as 5-year aggregated groups. Age group data for each state and territory were not available; therefore, variations in MND mortality across states and territories cannot be analysed by age. As a result, our analysis relied on unadjusted mortality rates for state-level comparison. Although age may be a contributing factor, it does not fully account for the differences observed across jurisdictions. The use of the year of registration is consistent with national reporting practices, rather than the year of death, although the difference between the two is generally minimal. The comparability of mortality data over time should be interpreted with care due to changes in ICD codes, which were not entirely identical. In addition, diagnostic and reporting practices may have influenced historical data, and atypical or slowly progressive forms of MND may also have been under-represented.

4.2 | Conclusion

Mortality due to MND has increased over recent decades. We hypothesise that is likely driven by the complex interplay between increased exposure to environmental risk factors and the underlying genetic architecture of MND. A nationwide effort is required to address this public health issue, and policymakers should support systematic reporting and investigation of this fatal disease, accounting for 1 in 234 Australian deaths.

Author Contributions

Conceptualisation: Carol M. Y. Lee, Dominic B. Rowe. Methodology: Carol M. Y. Lee, Rupendra N. Shrestha, Julian Gold, Mark Stevenson, Dominic B. Rowe. Formal analysis: Carol M. Y. Lee, Dominic B. Rowe. Investigation: Carol M. Y. Lee, Dominic B. Rowe. Data curation: Carol M. Y. Lee, Dominic B. Rowe. Writing – original draft: Carol M. Y. Lee, Dominic B. Rowe. Writing – review and editing: Carol M. Y. Lee, Rupendra N. Shrestha, Julian Gold, Mark Stevenson, Kelly L. Williams, Lyndal Henden, Sandrine K. K. Chan Moi Fat, Zoe Zussa, Amanda Wright, Martin Jude, Mark A. S. Laidlaw, Willem J. R. Fokkink, Dominic B. Rowe. Visualisation: Carol M. Y. Lee, Dominic B. Rowe. Supervision: Dominic B. Rowe. Project administration: Carol M. Y. Lee,

Dominic B. Rowe. Funding acquisition: Dominic B. Rowe. All authors have read and approved the final manuscript.

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Disclosure

Not commissioned; externally peer reviewed.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The study data can be accessed by contacting the corresponding author.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** mja270168-sup-0001-supinfo.pdf.