

# Riluzole use and reasons for non-use in people with amyotrophic lateral sclerosis in Aotearoa New Zealand

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## ABSTRACT

Amyotrophic lateral sclerosis (ALS), the most common form of motor neurone disease (MND), is a neurodegenerative condition with typically short life expectancy. Riluzole, the only survival-prolonging medication funded in Aotearoa New Zealand, has high uptake in other developed countries.

**AIMS:** To quantify riluzole use in New Zealand, identify factors associated with its use and explore reasons for non-use.

**METHODS:** In 2025, people in New Zealand diagnosed with MND were invited to self-complete questionnaires. Data were collected via Qualtrics, exported to Excel and analysed using descriptive and inferential statistics. Respondents with progressive muscular atrophy or primary lateral sclerosis diagnoses were excluded from this analysis.

**RESULTS:** Of 115 respondents, 55 (48%) were currently taking riluzole, 14 (12%) had taken it previously and 42 (36%) had never taken it. Common reasons for non-use included riluzole not being offered and concerns about lack of effectiveness and/or side effects. Uptake was lower with bulbar onset than limb onset ( $p < 0.05$ ).

**CONCLUSIONS:** People with ALS in New Zealand have low uptake of riluzole, despite its survival benefits. Prescribers and people with ALS need up-to-date information about riluzole's benefit-risk profile to increase uptake and confidence in prescription and use. Liquid riluzole is needed in New Zealand to aid uptake.

Amyotrophic lateral sclerosis (ALS) is a devastating neurodegenerative disease that causes progressive paralysis, with patients facing a median survival of around 3 years from symptom onset.<sup>1,2</sup> Limited therapeutic interventions improve survival, though non-invasive ventilation<sup>3</sup> and a multidisciplinary team approach<sup>4</sup> have demonstrated meaningful benefits.

In Aotearoa New Zealand, riluzole stands as the sole approved and funded medication prolonging survival in ALS patients. Pooled analysis of three randomised controlled studies (RCTs) found at 12 months an average survival benefit of 2–3 months and slower decline in limb and bulbar function.<sup>5</sup> One of these studies found reduced mortality of 38.6% at 12 months and 19.6% at 21 months.<sup>6</sup> However, methodological limitations likely underestimated riluzole's therapeutic potential,<sup>7</sup> with participants beginning therapy an average of 2 years post-diagnosis, relatively short study durations and exclusion of participants surviving the trial period.<sup>7</sup> Observational evidence is inherently less robust than well-conducted RCTs but can address some of these deficiencies. Most more recent observational

studies, which include longer follow-up and earlier therapy initiation, suggest that riluzole may confer a median survival benefit of 6–19 months.<sup>7,8</sup>

Pharmac, New Zealand's drug funding agency, has funded riluzole tablets in New Zealand since 1 October 2013,<sup>10</sup> under special funding arrangements (Table 1).<sup>11</sup> Because people with ALS often have swallowing difficulties or rely on feeding tubes, the lack of a liquid option in New Zealand is a major practical challenge to administration. Australia, the United Kingdom, the United States and Spain, among other countries, address this problem by providing and publicly funding riluzole in tablet and liquid form.

The study aim was to assess riluzole uptake by people with ALS in New Zealand, explore reasons for non-use and discontinuation and examine adherence patterns to inform policy decisions around riluzole funding and formulation provision.

## Methods

The Central Health and Disability Ethics Committee approved the MND Insight Research (2025 EXP 21804). This nationwide study explored the

**Table 1:** Subsidy criteria for riluzole in New Zealand.<sup>11</sup>

<p><b>Special authority criteria for funding</b></p> <p><b>Initial application</b></p> <p>This application can only be made by a neurologist or respiratory specialist, with approvals valid for 6 months. The criteria require that the patient:</p> <ul style="list-style-type: none"> <li>• has amyotrophic lateral sclerosis with disease duration of 5 years or less, <b>and</b></li> <li>• has at least 60% of predicted forced vital capacity within 2 months prior to the initial application, <b>and</b></li> <li>• has not undergone a tracheostomy, <b>and</b></li> <li>• has not experienced respiratory failure, <b>and</b></li> <li>• is ambulatory, <b>or</b> can use upper limbs <b>or</b> is able to swallow</li> </ul> <p><b>Renewal applications</b></p> <p>These applications are from any relevant practitioner with approvals valid for 18 months before reapplication is necessary. The criteria require that the patient:</p> <ul style="list-style-type: none"> <li>• has not undergone a tracheostomy, <b>and</b></li> <li>• has not experienced respiratory failure, <b>and</b></li> <li>• is ambulatory, <b>or</b> able to use upper limbs <b>or</b> is able to swallow</li> </ul>
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experiences and needs of people affected by motor neurone disease (MND) and their families. It recruited three participant groups: people with MND, family members and bereaved individuals. Only participants with MND were asked about riluzole use. Eligible participants were over 16 years of age, had a diagnosis of MND and lived in New Zealand. Family carers and the bereaved were defined as the key supporter of a person diagnosed with MND who either was currently living with MND (family carers) or had died in the last 2 years (bereaved). Exclusion criteria applied to anyone under 16, individuals not residing in New Zealand and those without a diagnosis of MND.

Recruitment occurred through two primary channels from 11 March to 20 April 2025. Motor Neurone Disease New Zealand (MND NZ) emailed study invitations and participant information sheets on four occasions to clients accepting communications, reaching 247 people with MND. Those without email addresses who accepted communications received postal invitations once. MND NZ support advisors could also mention the research at their discretion to clients not on the communications list. Additionally, the New Zealand MND Registry emailed invitations four times to their 201 registrants with MND, most of whom were likely also MND NZ clients.

The research tailored questionnaires for each participant group. This paper reports on the questions for people with MND ascertaining riluzole use (including reasons for non-use and discontinuation), self-reported riluzole adherence, clinical history (diagnosis and symptom onset dates, plus initial symptoms), the healthcare setting for the diagnosis (public versus private), demographic information, and the ALS Functional Rating Scale Revised (ALSFRS-R). Participants reported their specific MND diagnosis from options including ALS, primary lateral sclerosis, progressive muscular atrophy, progressive bulbar palsy, and “*I only know it as MND*” or “*other, please specify*”. Incidental references to riluzole by family members and bereaved participants in any open-ended responses were included in the data analysed.

Disease progression rates were calculated using a standardised formula: subtracting the current ALSFRS-R score from 48 (the maximum possible score) and dividing this by the number of months since symptom onset. Given that New Zealand restricts riluzole funding to people with ALS, the analysis excluded respondents with diagnoses of primary lateral sclerosis, progressive muscular atrophy, neuronal intranuclear inclusion disease or any other variants that two neurologists agreed were unlikely to be ALS. Multiple completion methods accommodated

participant preferences and abilities. People with MND could complete questionnaires online (with Qualtrics), on paper or by telephone. Family members and the bereaved used online or paper formats only. All paper and telephone responses were entered into Qualtrics for consistency.

Data were exported from Qualtrics into Excel. Duplicates and those with insufficient data were removed. For people with MND, responses from the three questionnaires were matched by individual participant to create one complete file. The analysis employed descriptive statistics as the primary approach, with Fisher's exact tests for nominal data and Mann–Whitney U tests for interval data to assess statistical significance. Qualitative responses were analysed by grouping similar responses, with quotes based on typicality or informativeness.

## Results

Of the estimated 285 people with MND who received written information about the research, 142 completed the first questionnaire (49.8% response rate). This represents 35.5% of the estimated 400 people with MND in New Zealand. Twenty-seven responses were excluded based on a diagnosis of primary lateral sclerosis (n=18), progressive muscular atrophy (n=6) or other diagnoses considered atypical ALS (n=3), leaving 115 responses for analysis.

The sample comprised 74 males (64.3%) and 41 females (35.7%). Most participants were born in New Zealand (n=95; 82.6%). Most (87.8%) identified as NZ European, with seven (6.1%) identifying as Māori, two (1.7%) as Pacific peoples, three (2.6%) as Chinese, two (1.7%) as Indian and six reporting other ethnicities—all European (5.2%). Two-thirds of the participants (n=76, 67.1%) had been diagnosed in 2022 or later (range 2000–2025). The median age was 67 years with 25% aged 58 years or less, and 25% aged 72 years or older. Thirty respondents (26.3%) appeared to have bulbar onset, 84 (73.7%) had spinal onset and one onset was unclear.

Sixty per cent of the sample had taken riluzole before, with 48% currently taking this medication (Table 2), reflecting a 20.3% discontinuation rate.

Those who had never taken riluzole cited various reasons (Table 2), with most reporting having never been offered it, never having it prescribed or having not heard of it. Five respondents said their neurologist had recommended against it, did not recommend it or would not prescribe it

for them.

Concerns about lack of effectiveness were common, with participants sometimes reporting that their neurologist had indicated the medication had little effect. Two respondents reported that a 3-month survival gain was insufficient justification.

*“After being given the information that I may only get around 3 extra months of life I opted not to take it and instead started taking natural supplements...”*

Other reasons for declining riluzole included the view that the risk of side effects and impact on quality of life outweighed the potential benefits:

*“After consultation with my neurologist, I decided that the possible slight life extension was not worth the side effects. Plus I would've had to give up coffee, and coffee brings me joy.”*

Indeed, among the 14 respondents who had discontinued riluzole, the most common reason was side-effects, including itchy rash, tiredness, nausea, diarrhoea, blurred vision and “kidney issues”. One person reported that riluzole “compromised my immune system”, resulting in hospitalisation with a high temperature. Two of the three respondents who stopped because of concerns about lack of effectiveness noted no benefit.

Of those currently taking riluzole, 43 (81.1%) reported missing no doses in a typical week. Reasons for missing doses were attempting to time doses to avoid fatty meals or food entirely (n=5), forgetting (n=4), changes in routine (n=3) and tiredness or oversleeping (one each):

*“I sometimes miss the evening one. I intend to take it two hours after dinner (empty stomach) and then I forget.”*

One respondent missed doses because of swallowing difficulties but achieved complete adherence after having a feeding tube inserted. Another respondent had only ever been prescribed riluzole once daily. Several factors were associated with riluzole use (Table 3). Uptake was significantly lower among those diagnosed in the private health system, those with bulbar onset, and those diagnosed before 2013 when riluzole funding started.

One family respondent reported difficulty with

**Table 2:** Riluzole usage and reasons for non-use.

	<b>N (%)</b>
Currently take riluzole	55 (47.8)
Previously took riluzole	14 (12.2)
Never taken	42 (36.5)
Missing data	4 (3.5)
Total	115 (100)
<b>Reasons riluzole was never taken*</b>	<b>N=42</b>
Never offered it/never prescribed it/never heard of it	13 (30.9)
Concern about lack of effectiveness	10 (23.8)
Concern about side effects	7 (16.7)
Specialist recommended against it or would not prescribe it for them	5 (11.9)
Not needed	3 (7.1)
About to start (one having respiratory test first)	2 (4.8)
Other	3 (7.1)
No reason provided	3 (7.1)
<b>Reasons for stopping riluzole*</b>	<b>N=14</b>
Side effects	10 (71.4)
Insufficient effectiveness	3 (21.4)
No reason given	2 (14.3)

\*Some respondents gave more than one reason.

crushing riluzole with the “casing” not dissolving and getting stuck going into the feeding tube. Another family respondent stated:

*“The specialist was terrible... When asked about any meds that might help, [they] said there is one that has a history of adding 1-to-2-months, but never offered it and basically dismissed it. Well with MND, 1-to-2-months extra to a person diagnosed with it is a lot.”*

## Discussion

This research found that 48% of respondents with MND were currently taking riluzole, with

many not taking it due to concerns about lack of effectiveness and side effects. Some reported not being offered the medication or being advised against it. Reasons for discontinuing treatment included possible side effects and concerns about lack of effectiveness. High self-reported adherence was noted. Uptake was reduced in respondents with bulbar onset, those diagnosed by a private specialist and those diagnosed before 2013. Our uptake rate is substantially lower than rates from four European ALS centres (83% taking riluzole),<sup>9</sup> an audit of French ALS centres (100% offered and 88% initiated within 2 months of diagnosis),<sup>12</sup> an audit from Northern Ireland (91%),<sup>13</sup> an audit from a tertiary ALS centre in Pennsylvania, United States (91% initiated riluzole)<sup>14</sup> and an

**Table 3:** Riluzole use by sub-groups from respondents who had ALS.

		Ever taken riluzole N (%)
Sex	Female (n=39)	23 (59.0)
	Male (n=72)	46 (63.9)
Feeding tube	Needs tube feeding (n=19)	12 (63.2)
	Does not need tube feeding (n=92)	57 (62.0)
Progression	Slow progression* (n=48)	27 (56.3)
	Intermediate progression* (n=57)	38 (66.7)
	Fast progression* (n=6)	4 (66.7)
Where diagnosed**	Diagnosed in the private system (n=50)	23 (46.0)
	Diagnosed in the public system (n=60)	45 (75.0)
Site of onset**	Limb onset (n=81)	55 (67.9)
	Bulbar onset (n=29)	13 (44.8)
Year diagnosed**	Diagnosed before 2013 (n=11)	2 (18.2)
	Diagnosed after 2013 (n=100)	67 (67.0)
Ethnicity	European (n=98)	59 (60.2)
	Māori or Pacific (n=8)	6 (75.0)

\*Slow progression is  $\leq 0.31$  ALSFRS-R change/month, intermediate is 0.32-1.17/month, fast is  $\geq 1.18$ /month.

\*\* $P < 0.05$ , Fisher's exact test.

audit from three Italian regions (61-85%).<sup>15</sup> A 2025 Australian MND patient survey found a 76% uptake, although the response rate was 8%.<sup>16</sup> The Pooled Resource Open-Access ALS Clinical Trials (PRO-ACT) data reported 80% riluzole uptake in phase two and three ALS clinical trial participants versus 65% in the United States ALS patient registry.<sup>17</sup> However, our uptake was higher than the rate documented in Scotland (86% offered and 40% taking riluzole).<sup>18</sup> High uptake might reflect a different experience for patients in ALS centres versus treatment in neurology or gerontology outside of an ALS centre as is common in New Zealand. Supporting this suggestion is a finding from Spain of 30% riluzole uptake under a general neurologist versus 89% for those treated in a multidisciplinary care clinic.<sup>4</sup>

The special authority criteria might reduce uptake in New Zealand; however, it is expected that most people with ALS would meet the diagnostic criteria at diagnosis and none discontinuing

riluzole cited cessation of funding. New Zealand has nearly identical access criteria to Australia,<sup>19</sup> but it likely differs from other countries.

Other research has found lower riluzole uptake with increasing age of the person with MND,<sup>15,18</sup> but age was not associated with uptake in our study.

Our discontinuation rate of 20% was higher than registry data in Scotland (15%),<sup>18</sup> a single hospital audit in Portugal (14%)<sup>20</sup> and a single clinic audit in Pennsylvania (17%)<sup>14</sup>. In the Portuguese study,<sup>20</sup> discontinuation was primarily attributed to concerns about lack of effectiveness, with only one person discontinuing due to side effects. Reasons for the Pennsylvania discontinuations included side effects (32%) with some restarted on a lower dose, and cost (15%).<sup>14</sup> The high rate of self-reported adherence in our study aligns with the Portuguese study<sup>20</sup> and is similar to Pennsylvania where adherence was lower immediately after initiation and late in the disease.<sup>14</sup>

## Implications

The low uptake in New Zealand appears largely driven by beliefs about ineffectiveness stemming from early findings that showed a small 2-to-3-month survival benefit, alongside concerns about side effects. Given the significant methodological deficiencies in these studies, and the fact that most observational studies suggest extended survival benefits of 7–11 months,<sup>7,9</sup> better dissemination of information about effectiveness to diagnosing clinicians appears necessary. The riluzole data sheet (prescribing information) still references the 2-to-3-month survival benefit,<sup>21</sup> and, until recently, so did the webpage for patients from MND NZ. One family member's observation of a benefit of even a short additional survival period provides a potent reminder to present survival information objectively without pre-judging treatment decisions. Other concerning prescribing practices include one person reporting being prescribed only one tablet daily and another believing they could not use riluzole with caffeine. While listed in the riluzole data sheet, caffeine is not known to be a clinically relevant inhibitor of CYP1A2 and no clinically significant interaction is expected.<sup>22</sup> Some respondents identified concern about side effects as a reason for non-use, potentially unaware that riluzole is generally well-tolerated.<sup>25</sup>

Liquid riluzole is unavailable in New Zealand, unlike many other health systems. Given that people with MND frequently have swallowing difficulties and some require feeding tubes necessitating tablet crushing—a time-consuming task that reduces drug delivery<sup>23</sup> and risks tube blockage—liquid riluzole is urgently needed in New Zealand. This could improve uptake in people with bulbar presentation (who had lower use) and reduce the care burden on family members who already undertake many tasks for people with ALS who often have poor hand function.

## Strengths and weaknesses

The study achieved a good response rate and, beyond understanding uptake and adherence patterns, identified specific reasons for non-use, discontinuation and adherence challenges with riluzole. However, several limitations should be acknowledged.

The reliance of the research on self-reporting

may have over-estimated adherence and reduced the accuracy of other data collected, such as the ALSFRS-R scores. We used self-reported diagnoses, and some participants reporting only “MND” might have had primary lateral sclerosis or progressive muscular atrophy. However, given the life-changing nature of the disease, persons with MND likely remember accurately their onset time and diagnosis date. Disease progression rates were calculated using ALSFRS-R scores at questionnaire completion, divided by months since onset. The non-linear nature of ALSFRS-R progression<sup>24</sup> may have affected calculations compared to studies calculating this metric earlier in the disease course.

Our sample may not represent all people in New Zealand with MND. It included relatively few fast progressors and many slow progressors, likely reflecting the survival benefit of slow progression and the challenges faced by those with rapid decline. The sample included more people with higher function than lower function, possibly reflecting reduced energy and capability for completing the questionnaire as function declines. The 6-week data collection period may have limited participant numbers and faster progressor inclusion. We had relatively few non-European respondents, although this could partly reflect the relatively low numbers of Māori with MND,<sup>25</sup> and the MND prevalence in countries with high non-European ethnicity is often lower than those with European ethnicity.<sup>26</sup> We did not ask reasons for taking riluzole, which may have revealed differences in discussions with the prescriber.

## Conclusion

Riluzole uptake among people with ALS in New Zealand is suboptimal, which is particularly concerning given that it is the only funded medicine shown to lengthen survival in ALS. Health services and clinicians should promote its appropriate use and update guidance to address outdated perceptions of riluzole's effectiveness and safety. Making liquid riluzole available and funded would facilitate prescribing and use in people with swallowing challenges, including those with bulbar onset ALS, and those using a feeding tube.

**COMPETING INTERESTS**

NG has amyotrophic lateral sclerosis and has no other interests to declare. All other authors have no interests to declare.

We accept full responsibility for the conduct of the study, for our access to the data and for our decision to publish.

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