

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

**Special authority criteria for funding**

**Initial application**

This application can only be made by a neurologist or respiratory specialist, with approvals valid for 6 months. The criteria require that the patient:

- has amyotrophic lateral sclerosis with disease duration of 5 years or less, **and**
- has at least 60% of predicted forced vital capacity within 2 months prior to the initial application, **and**
- has not undergone a tracheostomy, **and**
- has not experienced respiratory failure, **and**
- is ambulatory, **or** can use upper limbs **or** is able to swallow

**Renewal applications**

These applications are from any relevant practitioner with approvals valid for 18 months before reapplication is necessary. The criteria require that the patient:

- has not undergone a tracheostomy, **and**
- has not experienced respiratory failure, **and**
- is ambulatory, **or** able to use upper limbs **or** is able to swallow

**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.

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

		<b>Ever taken riluzole N (%)</b>
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.