



Riluzole

Information Sheet

What is riluzole?

Riluzole (brand name Rilutek) is the only medicine funded for the treatment of MND (ALS variant) in New Zealand. Riluzole 50 mg tablets are taken twice a day with a glass of water.

How effective is riluzole?

While two early trials showed that riluzole led to a median increased survival of 2-3 months compared to a placebo, these trials had limitations¹. The trials were relatively short, included people who started riluzole a long time after their MND diagnosis, and the survival information excluded results from people who were still alive when the trial finished¹.

So real life studies have been used since then to get a better understanding of how much survival increases with riluzole use when it is started soon after diagnosis and used for a longer time. These studies vary in how much longer people lived on taking riluzole compared with not taking it. Most of these have shown on average 7-11 months longer survival, depending on the study^{1,2}. Results will vary in different people. Starting riluzole early and continuing long-term is recommended for best effect^{1,3}.

Riluzole does not stop progression completely – increasing muscle weakness and loss of ability will still continue. A person taking riluzole, will not usually be able to tell whether it is working or not working for them.

Side effects

Most people will not get side effects when taking riluzole. A small number of people will get an upset stomach or weakness⁴. About 10% get a change in liver enzymes, so a blood test for liver enzymes is done before starting riluzole, then regularly after starting riluzole.

Signs of a liver problem include severe upper stomach pain, itching or yellowing of the skin – report these promptly to the doctor. Rarely an important lung problem can happen, so report a dry cough or shortness of breath to your doctor⁴.

If you think you might have a side effect, talk to your health professional. For more information see <https://www.medsafe.govt.nz/consumers/cmi/r/rilutek.pdf> or talk to your health professional.

Who can have riluzole funded?

Most people in New Zealand who have been newly diagnosed can have riluzole funded.

A neurologist or respiratory specialist applies for permission to get funding, and they have to confirm the person has amyotrophic lateral sclerosis (ALS), meets the required respiratory function, and has at least one of the following: can walk, can use arms or can swallow. This funding approval lasts for 6 months and after that it needs to be renewed – your family doctor can do this. This renewal lasts 18 months before it needs a further application and there are set criteria for this.

Riluzole will be given one month at a time. However, people with poor mobility (e.g. difficulty walking or in a wheelchair) can ask their pharmacist for three months at once on the basis of mobility difficulties. This applies to many medicines.

How to take riluzole

See the consumer medicine information on how to take riluzole with respect to food.

<https://www.medsafe.govt.nz/consumers/cmi/r/rilutek.pdf>

As with all medicines, talk to your pharmacist if you need advice on crushing the medicine to take or want to put into a feeding tube. They can look up information on how best to do this.

Discuss with your neurologist or other MND specialist if riluzole is right for you.

References

1. Andrews JA, Jackson CE, Heiman-Patterson TD, Bettica P, Brooks BR, Pioro EP. Real-world evidence of riluzole effectiveness in treating amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*. 2020;21:509-518 <https://doi.org/10.1080/21678421.2020.1771734>.
2. Vasta R, Fouke O, Frederik H, et al. Real-world prognostic role of riluzole use in ALS: a multi-center study from PRECISION-ALS. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*. 2025;26:50-60 <https://doi.org/10.1080/21678421.2025.2472889>.
3. Thakore NJ, Lapin BR, Mitsumoto H, Pooled R. Early initiation of riluzole may improve absolute survival in amyotrophic lateral sclerosis. *Muscle and Nerve*. 2022;66:702-708 <https://doi.org/10.1002/mus.27724>.
4. Pharmacy Retailing (NZ) Ltd. Rilutek data sheet. Medsafe. Published 2022.

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