

# Riluzole for Motor Neuron Disease

## Information for patients

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### What is Riluzole?

Riluzole is currently the only drug licensed in the UK for the treatment of Motor Neuron Disease (MND). It is approved by the National Institute for Health and Care Excellence (NICE) and is available on the NHS. Riluzole is not a cure, but it may slow disease progression in some people.

### How does Riluzole work?

Muscle movement is controlled by electrical signals sent from the brain through motor neurones. These signals pass between neurones using chemical messengers, including glutamate. In MND, glutamate may build up and damage nerve cells. Riluzole is thought to work by reducing the harmful effects of glutamate build up, which may help slow further damage to motor neurones.

### What are the benefits of Riluzole?

Riluzole does not reverse existing nerve damage. Studies show it may:

- slightly slow disease progression
- extend survival by several months on average.

Benefits vary between individuals and cannot be predicted. Some people also feel psychological benefit from taking a treatment that may help extend survival. Taking Riluzole soon after diagnosis may offer the greatest benefit, although it will not reverse existing symptoms.

### How is Riluzole taken?

Riluzole is available as:

- tablets
- liquid (useful if swallowing is difficult or a feeding tube is used)
- oro-dispersible film (dissolves on the tongue).

Your healthcare team can advise on the most suitable form. Different brands may look different but contain the same active ingredient. Taking Riluzole on an empty stomach (1 hour before or 2 hours after food) may reduce nausea.

### What are the possible side effects?

Riluzole is usually well tolerated. Possible side effects include:

- gastro-intestinal disturbances
- Fatigue or weakness
- headache
- numbness or tingling
- dizziness (which may affect driving)
- Abnormal liver function tests (LFTs).

Rare side effects include blood cell changes, liver problems, and lung problems (such as a dry cough with breathlessness). Some breathing or coughing symptoms may be related to MND itself, so please report any new or worsening symptoms to your MND Clinical nurse specialist or MND consultant, or GP.

Side effects are usually mild and may improve if the dose is reduced or stopped under medical supervision. There are no known withdrawal effects if Riluzole is stopped.

## Monitoring and safety

- LFTs will be checked prior to starting treatment, monthly for the first 3 months, every 3 months for the remainder of the first year and periodically after that
- Patients should report any febrile illness (temperature higher than 38°C) to their medical team promptly
- Patients should report any new dry cough or shortness of breath to your medical team.

Riluzole is not recommended if you have significant liver, kidney, or heart problems, or during pregnancy or breastfeeding.

## Dosage

Riluzole tablets are 50mg. The usual dose is 100mg per day, taken as 50mg twice daily (12 hours apart), ideally at the same times each day before food.

Some users have found it beneficial to phase in the medication to reduce the likelihood of potential side effect. They do this by taking 50mg at night for two weeks and then introduce the morning dosage of 50mg making the daily dose after two weeks of 100mg.

If a dose is missed, take the next dose at the usual time. **Do not take a double dose.**

## Do I have to take Riluzole?

No. Your Neurologist will advise whether Riluzole is suitable, but the decision to take it is yours.

## Where can I get Riluzole?

If recommended by your Consultant, and you choose to take Riluzole, it is available on NHS prescription. It is started by a Neurologist and continued by your GP. This is as per the Lothian Shared Care Agreement (approved September 2024).

National Institute for Health and Care Excellence (NICE) recommends Riluzole for MND, meaning the NHS is required to fund it when appropriate. If needed, your Neurologist can continue prescribing.

In most cases, access to Riluzole is straightforward once prescribed.

If you would like more information you can contact the Advanced MND Nurse Specialists: [loth.mndservice@nhs.scot](mailto:loth.mndservice@nhs.scot)

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