

Patient Information: Treatment with Riluzole – What should I expect?



What is Motor Neurone Disease?

Motor Neurone Disease (MND) is the name given to a group of diseases that affect motor neurones in the brain and spinal cord.

Motor neurones are a type of nerve cell along which, the brain sends instructions, in the form of electrical signals, to the muscles. If these cells stop working properly it leads to weakness and wasting of muscles.

MND is generally a progressive disease which means symptoms often become more severe over time. The rate of progression can vary greatly from one person to another.

Amyotrophic lateral sclerosis (ALS) is the most common form of MND, accounting for 8 out of 10 of all MND cases.

What is riluzole (Rilutek)?

Riluzole is a medicine that can be used to treat ALS. It is not a cure and it will not reverse damage but research has shown that it can prolong survival.

How to take riluzole?

Riluzole is available as a tablet or liquid and the recommended dose is 50mg twice daily about 12 hours apart. It should be taken on an empty stomach, for example 1hr before food or 2hrs after food.

When should riluzole be used?

The National Institute for Health and Care Excellence (NICE) is a part of the NHS. It examines published evidence and produces guidance for both the

NHS and patients on how medicines and other treatments should be used.

NICE have recommended that:

- Riluzole should be available for patients with ALS, but should only be started by a specialist with experience of treating MND.
- After riluzole has been started by a specialist, General Practitioners (GPs) can continue treatment, but they should only do this when there is a formal arrangement with the specialist, which is known as a Shared Care Agreement.

What is a shared care agreement?

For some medicines, tests have to be carried out to make sure that the medicine is not upsetting your body or causing side effects.

The manufacturer of riluzole has outlined what tests are needed and how often they should be done.

The shared care agreement makes it clear if these should be done by the specialist or if they can be done by your GP.

What are the possible side effects of riluzole?

Like all medicines riluzole can cause side effects, but not everyone will get them.

Common side effects include abdominal pain, dizziness, tiredness or lack of energy, headaches, a tingling or burning feeling in the mouth, an increase in

heart rate, feeling sick or vomiting and diarrhoea.

Riluzole can also cause impaired liver function and increased levels of liver enzymes, decreased numbers of white blood cells (which makes it more difficult for your body to fight infections) and anaemia. Blood tests will be done to check for these.

Blood tests will also be done to check how well your kidneys are working.

You should tell your doctor if you have:

- Yellowing of the skin or whites of your eyes, itching all over or if you're feeling sick or being sick.
- If your kidneys are not working very well.
- If you have a temperature or fever.
- If you have a cough or are having difficulties breathing, (this may be a sign of lung disease related to riluzole).

What will my specialist be responsible for?

Your specialist will advise if riluzole is a suitable treatment for you. If you then decide that you would like to start treatment, they will be responsible for:

✔ Medicines

The specialist will prescribe and monitor riluzole for the first year of treatment to ensure it is working and there are no safety concerns.

✔ Tests

Blood tests are needed every month for the first three months, then every three months for the first year to check;

- Liver function
- Full Blood Count
- Kidney Function

✔ Advice on Symptoms

You will be advised on how to recognise potential side effects of the medicine.

Your specialist will also tell your GP about any changes to your health or medicines.

What will my GP be responsible for?

✔ Medicines

After the first year of treatment, if treatment is working for you, you will get your medicines through your GP in the normal way.

✔ Tests

You will need blood tests once a year to check;

- Liver function
- Full Blood Count
- Kidney function

✔ Your On-going Health

Your GP will monitor your on-going health and wellbeing and report any changes in your health or side effects of treatment to your specialist. This may result in you having extra tests, or your treatment being stopped.

Do you want more information?

For more information about how to take riluzole and common side effects, speak to your doctor. Written information will also be provided with your medicine supply.

For MND Care Centre based at Royal Preston Hospital

Telephone 01772 522545

To find out more about MND visit www.nhs.uk and search for Motor Neurone Disease.

For the Motor Neurone Disease Association
<http://www.mndassociation.org/>