



RILUZOLE : QUESTIONS AND ANSWERS

This information sheet aims to answer some common questions about the drug Riluzole (trade name Rilutek).

Why might Riluzole be effective in treating MND?

Riluzole is an anti-glutamate agent that inhibits the amount of glutamate released in the CNS. By neutralising the glutamate effect, less damage would be done to motor neurones.

How does Riluzole work?

Riluzole has several mechanisms of action. It appears to block the effects of glutamate acid on glutamate receptors and inhibits the release of glutamate from nerve terminals.

What is glutamate?

Glutamate is most commonly found in the brain. It is a single amino acid that acts as the major neurotransmitter in the central nervous system. It plays an important role in fast transmission of nerve signals. In excess, glutamate can become “excitotoxic” i.e. may be overactive in key areas of the brain and spinal cord in MND and, over a period of time, may cause nerve damage.

Is survival increased?

The results of trials indicated that more people with MND receiving a daily 100mg dose of Riluzole remained alive at the end of the trial as compared to those on placebo.

Is there any effect on the rate of muscle function deterioration?

It is quite difficult to measure a slowing down in the rate of deterioration in muscle function in people with MND as the tests are quite crude. In the first trial of 155 patients a significant reduction in the rate of deterioration was demonstrated using

manual muscle testing. However, these results were not replicated in the larger study.

What are the main side effects?

The most common side effects are asthenia (fatigue), nausea and rarely elevated liver enzymes.

Can an individual determine if the drug is working?

No, an individual cannot determine if the drug is working. The survival benefit observed in the second trial is based on analysis of 959 people.

How does Riluzole effect individuals?

At present, it is not possible to predict the individual response of a person with MND to Riluzole or to predict the natural course of the disease, if untreated.

Is Riluzole a real therapeutic advance?

Rilutek is an important first step in the treatment of MND where there are no other approved treatments to date. It is not a cure, but it is the first medicine to show a modest impact on survival for people with MND.

Will Riluzole work for me?

As with all medicines it may not be suitable or beneficial to everyone. This will need to be discussed with your neurologist.

Are there any tests needed before taking Riluzole?

As with any drug it will be necessary to establish that there are no physical reasons why the drug should not be used.

How often will I be followed up by the prescribing doctor?

This will be at the discretion of the neurologist. However, it is likely that the prescribing doctor will arrange for blood tests, to check for side-effects, to be conducted on a regular basis, monthly for the first 3 months and quarterly for the remainder of the year and periodically after that.

If I am on other medication will I still be able to take Riluzole?

This should be discussed with your physician.

If other drugs for MND come along can I take them both?

A number of other drugs are being developed and tested and there are plans to assess Riluzole in combination with these. Please discuss with your neurologist.

What form does the medication take?

It is in tablet form taken twice a day.

Can I take it if I have swallowing difficulties or have a gastrostomy?

Yes, the tablets may be crushed and mixed with a teaspoon of sugar to aid swallowing, or alternatively the tablets may be crushed and the powder mixed with a soft food product such as a puree, yoghurt or into a thick beverage and eaten in the usual way.

It is not recommended that the powder be mixed with liquid (i.e. water) as sedimentation may occur. Sedimentation could result in an incomplete dose being given and may also produce local anaesthesia in the mouth.

If you have a gastrostomy it may be easier to administer the tablet directly into the tube. Alternatively follow the instructions for swallowing (see above) and administer the 'mixture' via a syringe directly into the tube.

I have had MND for some time. Is it worth taking Riluzole?

This should be discussed with your neurologist. The trial results did not clearly identify whether Riluzole benefited one particular group of people with MND more than another.

What happens if I stop taking it?

The information from the trials did not indicate that there were any harmful effects from suddenly ceasing to take Riluzole.

What if I am refused Riluzole for medical reasons?

Sadly there is nothing else that can be done if you have been informed in writing that there are medical reasons why the drug is not suitable for you.

How can I find out more?

If you would like to talk to someone about Riluzole please contact the MND Helpline: 08457 626262, your RCA or Volunteer Visitor.

