



WHAT IS RILUZOLE?

Riluzole, also called Rilutek, is presently the only licensed medication specifically approved for MND (Motor Neurone Disease). This is not a cure but may slow down the progression of the condition. Riluzole is manufactured by the drug company Sanofi-Aventis (formerly Aventis).

IS RILUZOLE AVAILABLE ON THE NHS?

Yes! Following pressure from the Scottish Motor Neurone Disease Association all NHS Health Boards in Scotland prescribe Riluzole on the NHS. If you wish to begin taking Riluzole talk with your GP or Clinical Specialist / Care Advisor.

HOW DOES IT WORK?

Motor neurones are thought to be damaged by an excess of glutamic acid (glutamate), a naturally occurring amino acid that is found in the body. Glutamate is a substance that is produced in the normal functioning of the nervous system.

However in MND it is thought there is an inability to remove glutamate that has been used by nerve cells resulting in a build up of the substance, which may cause damage to the nerves by poisoning them.

Riluzole has an inhibitory effect on glutamate release thus reducing the build up of glutamate outside the nerve cells and protecting them from damage by it.

Riluzole has been shown in clinical trials to increase survival by a small amount by slowing the rate of nerve damage.

WHAT ARE THE MAIN SIDE EFFECTS?

Most people tolerate Riluzole, however side effects have been noted. The most common side effects include fatigue, nausea and elevated liver enzymes. Your neurologist or GP will take a routine blood sample prior to Riluzole treatment. For the first 3 months you will have your blood tested every month, thereafter, it will be done three monthly for the first year and then on a periodic basis.

DOSAGE

Riluzole comes in tablet form of 50mg/tablet and the dose per day is 100mg. Riluzole should be taken at the same time each day - for example morning and evening before food. If a dose is missed the next tablet should be taken at the usual time and the missed dose should not be taken.

Some users have found it beneficial to phase in the medication to reduce the potential side effects. They do this by taking 50mg at night for two weeks (first two weeks daily dose is 50mg) and then introduce the morning dosage of 50mg

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

making the daily dose after two weeks of 100mg.

CAN I CRUSH THE TABLET?

Yes the tablets can be crushed if you have difficulty swallowing. The crushed tablet should then be mixed with soft food, such as puree, jam or yogurt, to aid swallowing. The powder should not be mixed with liquid as sedimentation may occur and result in an incomplete dose being given.

WHO PRESCRIBES RILUZOLE?

Your Neurologist may suggest the prescription of Riluzole to your G.P. who will be the normal source of your prescriptions. The prescription is normally for a 3 month supply.

WHERE CAN I GET MORE INFORMATION?

Contact your Neurologist GP or local MND Care Team Specialist. If you are unsure who your Care Team Specialist is please contact the Scottish MND Association on 0141 9145 1077 and we

will ask the Specialist for your area to get in touch with you.

I'VE BEEN TOLD BY MY LOCAL CHEMIST HE CAN'T GET THIS DRUG FOR ME. WHAT SHOULD I DO?

There is usually no problem with the overall supply of Riluzole. However, from time to time the manufacturers ask for evidence that the requested supply is for a real patient. If your pharmacist reports difficulty in obtaining supplies ask him or her to contact the Scottish MND Association on 0141 945 1077 and we will advise on how to go about obtaining a supply for you.

Sanofi-Aventis, the manufacturers of Riluzole, were concerned that supplies of the drug were finding their way onto the black market and stopped supplying wholesalers with all the supplies they requested. They would, however, supply the drug if the pharmacist faxed a copy of the prescription through to them. Unfortunately many wholesalers told pharmacists the drug had been withdrawn – **when it hadn't**. Supplies are always available, but sometimes this proof is required.

Further Information

Manufacturer's information on Riluzole

<http://products.sanofi-aventis.us/rilutek/rilutek.html>

Wikipedia Entry for Riluzole

<http://en.wikipedia.org/wiki/Riluzole>

Factsheet 39

Lithium