



### 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 MND Scotland 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 making the daily dose after two weeks of 100mg.

**MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.**

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### **CAN I CRUSH THE TABLET?**

It is not advised to crush the tablets as it may result in an incomplete dose being given.

If a liquid form is required, for example for PEG administration, there is a liquid suspension formulation of Riluzole called Teglutik which is available. More information about it can be found on the Teglutik website <http://www.teglutik.co.uk/>

### **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 MND Scotland on 0141 332 3903 and we will ask the Specialist for your area to get in touch with you.

### **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>

Manufacturer's information on Teglutik <http://www.teglutik.co.uk/>