



Information for
patients and
carers

Riluzole

Motor Neurone Disease (MND)
Care and Research Centre

What is Riluzole?

Riluzole has a modest effect in delaying disease progression, and can therefore prolong survival in Motor Neurone Disease (MND).

How does it work?

Nerve impulses are transmitted from one nerve to another. It is thought that excessively high levels of certain naturally occurring chemicals (particularly glutamate) damage the motor nerve cells, and this is thought to be a cause of MND.

Riluzole is thought to work by reducing the release of glutamate, thus helping to normalise the level of this chemical in the nervous system, and reduce its harmful effects.

How effective is it?

Riluzole does not stop the progression of the disease, it only slows it down. You will not see an improvement in your symptoms. However, it is hoped that the rate of deterioration will be slower if you are taking Riluzole. The medication seems to work best if it is started as early as possible after diagnosis, although the effectiveness of Riluzole can vary from one person to another.

How will I know if it is working?

You will probably not be able to tell if it is working. Riluzole does not have a noticeable effect on the symptoms of MND. It is however hoped Riluzole will slow down the progression of the disease over a period of time.

How is Riluzole taken?

Riluzole comes in tablet form; or in liquid form if you have swallowing difficulties. The recommended dose is 50mg taken twice a day which may be taken on an empty stomach to reduce the risk of some side effects.

Are there any special precautions I need to be aware of?

Before you start taking Riluzole you should inform the care centre if you have had any previous liver, kidney or heart diseases. You should not take it if you are pregnant, planning pregnancy or breast-feeding.

Does it have any side effects?

The most common problem is fatigue (which can be common in MND) and nausea. Riluzole may cause problems in liver function. The rare side effects are stomach ache, headache, vomiting, increased heart rate, sleepiness, allergic reactions or inflammation of the pancreas. If you are taking the liquid form, it can cause temporary numbness of the tongue and mouth.

You may also notice you are more prone to infections. There is the potential for dizziness or vertigo; you should not operate machinery if these symptoms occur. If you experience any fever you should seek advice from your GP.

The side effects are usually mild, but if they are troublesome then we would discuss a treatment plan with the neurology team. There are no known side effects from either stopping Riluzole gradually or abruptly if needed.

Do I have to have blood tests?

The prescribing doctor requires up to date blood results including full blood count (FBC), urea and electrolytes (U&Es) and liver function (LFT). These blood tests need to be taken each month for the first 3 months. If everything is normal, the tests are repeated every 3 months for 12 months and then every 6 months after that.

Can I take Riluzole with other medicines?

Riluzole rarely interacts with other medication. Check with your doctor, dentist or pharmacist before taking any new medications.

What happens if I take too much Riluzole?

If you accidentally take one tablet too many, it is not likely to have any effect. If you take several extra, consult your doctor. An overdose of Riluzole increases the risk of experiencing side effects.

What happens if I forget to take Riluzole?

Take it as soon as you remember, unless it is near your next dose. Do not take any extra tablets to make up for the tablets you have missed.

Who should get Riluzole?

Riluzole is considered for all patients seen at the MND Care and Research Centre, but is not always appropriate for everyone with MND. Riluzole is not safe to use if there are other major health problems such as abnormal liver function or kidney impairment.

Who supplies Riluzole?

Riluzole is a specialised drug; therefore the MND Care and Research Centre at Preston will normally provide it on a 2-3 monthly basis. You

need to ring the care centre when you have 2 week supply of tablets left. The office number is **01772 522545**.

If you are on the liquid form, contact the care centre when you start your last bottle. This will give us time to check your blood tests in order to monitor and adjust treatment as needed, get the prescription and allow for delivery time.

The MND Care Centre will supply the first 12 months of Riluzole, your GP will then take this over.

Contact details

Should you require further advice or information please contact Lancashire and South Cumbria MND team on: **01772 522545**.

References

Shared Care Guidelines 2015 Lancashire Medicine Management Group
www.lancsmmq.nhs.uk/media/1234/riluzole-shared-care-guideline-version-13.pdf

NICE, 2001, Guidance on the use of Riluzole (Rilutek) for the treatment of Motor Neurone Disease, TA20
www.nice.org.uk/Guidance/TA20

Motor Neurone Disease Association, 2017, Riluzole: Information for people with or affected by motor neurone disease
www.mndassociation.org/app/uploads/2015/07/5A-Riluzole.pdf

Summary of Riluzole characteristics
Riluzole 50mg Film-Coated Tablet - Summary of Product Characteristics (SmPC) - (emc) www.medicines.org.uk

Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.patient.co.uk

www.accessable.co.uk

www.mndassociation.org

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If you want to stop smoking you can also contact the Quit Squad Freephone 0800 328 6297.

Please ask if you would like help in understanding this information. This information can be made available in large print and in other languages.

Cantonese:

如果你希望以另外一種格式接收該資訊，請和我們聯絡，不必猶豫。

Gujarati:

જો તમને આ માહિતી બીજી રચના કે ફોર્મેટમાં મેળવવાની ઇચ્છા હોય, તો કૃપા કરી અમારો સંપર્ક કરતા અચકાશો નહિ.

Hungarian:

Kérjük, vegye fel velünk a kapcsolatot, ha más formában kéri ezt az információt.

Polish:

Jeżeli chciał(a)by Pan/Pani otrzymać niniejsze informacje w innym formacie, prosimy o kontakt.

Punjabi:

ਜੇ ਤੁਸੀਂ ਕਿਸੇ ਹੋਰ ਫਾਰਮੈਟ ਵਿਚ ਇਹ ਜਾਣਕਾਰੀ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਸਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰਨ ਤੋਂ ਨਾ ਝਿਜਕੋ।

Urdu:

اگر آپ اس معلومات کو کسی اور صورت میں حاصل کرنا چاہتے ہیں تو برائے مہربانی ہم سے رابطہ کرنے میں ہچکچاہٹ محسوس نہ کریں۔

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Division: Medicine

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