Riluzole

This information sheet explains how the drug riluzole works, with guidance on how it can be obtained and administered.

The benefits and limitations are both explored, with details about potential side effects.

All featured quotations are from people living with or affected by motor neurone disease (MND).

What is riluzole?

Riluzole is currently the only drug licensed for treating MND in the UK. The National Institute for Health and Care Excellence (NICE) has approved its use for MND, so it is freely available to people who have been diagnosed.

If appropriate for you, treatment with riluzole should only be initiated on the advice of a neurological specialist who is experienced in the management of MND. The routine prescription and supervision of riluzole may be managed by GPs, under an agreement known as a shared care arrangement with the specialist.

There is always the possibility that riluzole may not be suitable for you on medical grounds. If so, you should discuss this with your MND specialist, usually a neurologist, and be informed of this in writing.

Riluzole is not necessarily prescribed in every case of MND. For example, it may not be available for primary lateral sclerosis (PLS), which has a slower progression. This needs to be discussed with the consultant making the assessment.
How riluzole works

Muscles are controlled by electrical messages sent from the brain, which are transported through the motor neurone system.

These electrical messages are transmitted from one motor neurone to the next via the release of a chemical messenger. For many motor neurones this chemical messenger is a chemical called glutamate, but high concentrations of glutamate are toxic. Riluzole is thought to work by suppressing glutamate activity.

However, riluzole has many other actions too. The anti-glutamate effect may be a reason why it provides some benefit for people with MND, but this is not yet proven.

The benefits of riluzole

Riluzole is not a cure, and will not reverse any damage to the motor neurones already present. After 18 months of treatment, it may increase survival by two to four months on average. Those taking riluzole will not be aware of any difference in the symptoms of their MND, but taking this drug may marginally slow down the progression of the disease.

To get the maximum benefit from riluzole, it is probably better to start taking it earlier in the course of the disease.

The moderately beneficial effect for people with MND, comparing those taking riluzole with a control group taking a placebo, was shown as a result of four randomised controlled trials (which included 1477 participants at a number of UK centres, all with the common amyotrophic lateral sclerosis (ALS) type of MND).

It is not possible to apply results from large groups to predict whether riluzole will benefit any particular individual. This is partly because of the fact that MND progresses differently in each individual case.

Please note: those over 75 years of age were not included in the original trials and the trials did not measure either quality of life or information on long term survival (beyond 18 months).

Riluzole may only increase survival for a few months, but it is the only drug that alters the disease course for MND. In many cases this moderately beneficial effect offers positivity for people living with MND. A postal survey of 80 MND specialists suggested that people taking riluzole reported a positive effect on their psychological wellbeing.

Please note: Only those taking riluzole are permitted to take part in the majority of current clinical trials. This could also be the case for possible future trials (see Further information towards the end of this sheet to access more detail).
How riluzole is administered

Although not strictly necessary, side effects such as nausea are less likely if you take riluzole on an empty stomach (if possible, one hour before or two hours after a meal).

It comes in tablet form and should be swallowed whole, but if there are problems swallowing, the tablets may be crushed and mixed with a teaspoon of sugar to aid swallowing. Once it is crushed it should be taken immediately due to limited stability problems. Riluzole should not be dissolved in water as it does not dissolve well.

When crushed, the drug can produce a temporary numbing effect in the mouth. It may be easier to swallow if crushed and mixed with a soft food product such as a puree, yoghurt, ice cream or a thick beverage and eaten in the usual way.

Riluzole tablets can also be crushed for tube feeding, but ask for guidance from your health and social care team. This must be done correctly to avoid the risk of blocking the tubing.

Some people may wish to review their continued use of riluzole if it is difficult to administer, or in the latter stages of MND. If this is being considered, it may be helpful to discuss this with your specialist.

Known side effects:

Riluzole is well tolerated by most people, but side effects may include:

- nausea
- vomiting
- weakness
- extreme tiredness
- headache
- numbness
- dizziness (which may affect the ability to drive safely)
- bone marrow damage (resulting in anaemia or other blood cell problems)
- liver damage (very rarely)
- lung damage (very rarely, manifesting as a dry cough with difficulty breathing).

*Note: some people may have coughing and breathing problems related directly to MND, so please see your consultant should any relevant symptoms occur.*
These are not generally serious and can be improved by a reduction or by stopping the riluzole dosage under medical supervision. There are no known side effects if riluzole is discontinued gradually or abruptly, (see later heading What else can I do to take positive action?).

Monitoring for the rare possibility of liver damage is undertaken routinely by the GP who will request blood tests, usually monthly for the first 3 months, quarterly for the remainder of the year and then periodically.

Riluzole is not recommended:

- if there is problem with the function of the kidney, liver, or heart
- during pregnancy or breast feeding.

There is no evidence of any adverse effects due to a combination of riluzole and any other medication.

**Do I have to take riluzole?**

Your neurologist will determine if riluzole is appropriate for your condition, but it is still your decision whether to take this drug or not. This is a very personal decision and may be based on a variety of factors.

Some people find the taking of riluzole a positive action, which helps to provide a sense of control.

“Though the benefits may not be great, it at least gives hope that this is the step to greater things to come.”

Taking riluzole may also qualify you for certain clinical trials, if this is something you wish to consider (see Further information towards the end of this sheet to access more detail).

Others question whether the moderate benefit extends survival in a positive way or if prolonging life with a progressive condition will impact too much on quality of life. This is not a question that can be easily answered. Your particular circumstances and outlook are likely to influence how you feel about this.

“An extra two to four months may sound attractive to some people, but not others.”

Talking to your consultant may help you to make an informed decision about the drug, to suit your needs and preferences.
What else can I do to take positive action?

There is no drug alternative yet to riluzole. If you decide not to use this drug or if you have to stop taking it for any reason, you will not notice a difference and there are other ways to take positive action that will help you maintain a sense of control and achieve the best possible quality of life.

These might include:

- physiotherapy, which cannot reverse the effects of MND, but can help to maximise movement and mobility, and reduce discomfort
- complementary therapies, such as massage or reflexology, which for some people can help to alleviate symptoms and promote calm
- respiratory therapies or interventions to assist with any breathing difficulties
- proactive management of nutrition with advice from a dietitian
- other interventions to help with a variety of symptoms.

“One person used meditation and I think this is a very good way to cope and maintain hope…and music therapy if you are lucky to have access to this.”

Our other publications and our information sheets provide a wide range of guidance on symptom management, interventions, therapies and ways to take back control where possible (see Further information towards the end of this sheet for details about accessing our publications).

Being proactive about seeking help and discussing options with your health and social care team may provide a more positive pathway through the disease progression (see also the next heading Coordinated care).

Coordinated care

It is recommended that a coordinated multidisciplinary approach to care is important for increased survival and improvement of quality of life with MND.

This is usually linked to palliative care, which means support given beyond immediate primary healthcare when you have a serious or life shortening illness. This can include symptom control and other psychological, social, spiritual or religious needs. It also includes support for your family and carers.

“Quality palliative care plays an extremely important role in the treatment of the symptoms for MND, eg having the right equipment at the right time can make such a difference to how someone feels and how they live their life.”

Palliative care services are usually first accessed through referral by your GP. If you have been diagnosed with MND, it is worth asking your GP for
advice, as early referral can be beneficial. There may be a waiting period before you can access a palliative care team.

Each individual’s path through MND is different. You will not necessarily experience the same symptoms, or in the same order, as other people with the disease. The rate of progression can also vary. Some people may need assistance with respiratory issues and the provision of non-invasive ventilation (NIV). Others may require help with nutrition.

There are many combinations of assistance and a multidisciplinary team is comprised of specialist health and social care professionals. Among others, these may include a:

- neurologist
- clinical nurse specialist
- physiotherapist
- occupational therapist
- dietitian
- speech and language therapist
- respiratory management team
- specialist in palliative care
- MND Association visitor
- regional care development adviser (RCDA)

The MND Association part-funds a national programme of MND Care Centres and networks, where multidisciplinary expertise is provided. If you cannot access a Care Centre or network, you can also access multidisciplinary support from your nearest neurological clinic. Contact our helpline MND Connect for guidance or refer to Information sheet 16 - MND Care Centre programme.

(See Further information at the end of this sheet to access other publications – and for our helpline contact details.)

The provision of riluzole

If your consultant recommends that riluzole would be suitable for you, and you decide to take it, the drug is available by prescription (usually from your GP, via your local pharmacist).

Riluzole has been given a technology appraisal by the National Institute for Health and Care Excellence (NICE). A technology appraisal is an assessment by NICE of whether a medicine or therapy is effective. The appraisal resulted in a recommendation by NICE for riluzole to be used in
cases of MND. This recommendation technically covers England and Wales, but NICE recommendations are often taken into account in Northern Ireland and elsewhere.

Due to the NICE recommendation, the NHS is legally required to pay for riluzole when it is suitable for a patient. However, some GPs insist that it is prescribed by a hospital doctor for reasons of cost. Very often the cost of the drug will come out of the same budget, whether a GP or a hospital doctor prescribes it, so if your GP declines to prescribe riluzole you may wish to ask them whether they understand this. If they still refuse to prescribe, your neurologist should be able to issue a prescription instead, when appropriate.

In most cases there is no problem with the provision of riluzole once it has been prescribed, but there have previously been periods of delay due to temporary shortage in supply. The MND Association monitors disruption in the supply of riluzole and would appreciate any information related to this subject should you have any problems. Please contact our helpline, MND Connect, if you experience supply issues (see Further information at the end of this sheet for contact details).

Our arrangement with Dialachemist is one of the ways we have tried to ensure an improved supply (see next heading).

**Dialachemist: free home delivery prescription service**

In the past, riluzole could only be distributed by one licensed supplier, but this is no longer the case.

As a result, the MND Association has negotiated a home delivery prescription service with Dialachemist Ltd. This NHS registered online pharmacy is fully regulated by the General Pharmaceutical Council (GPhC).

They are staffed by fully qualified pharmacists and technicians, and deliver direct to your home or other nominated address across the UK.

The benefits are:

- free home delivery (no delivery cost to the recipient)
- a service tailored to individual need
- guaranteed on-going supply of riluzole
- direct interaction with trained professionals to address any concerns.
The home delivery prescription process:

1. To use the service, you need to be registered with Dialachemist. This can be done through their website or by telephone (see contact details below).

2. You need to send your prescription to Dialachemist. Your carer or MND Care Centre can do this on your behalf if required (freepost envelopes can be requested from Dialachemist).

3. The prescription will be processed by Dialachemist as soon as it is received and they can also provide other prescribed items for the registered individual, as requested.

4. Each prescription will be delivered by guaranteed next day delivery to the home or other nominated address.

5. You can request a prescription reminder service, using your preferred method of communication, 10 days before the prescription is due.

6. If you or your carer have any queries about the service, contact Dialachemist. Their team have been trained by the MND Association to provide support as appropriate.

The full contact details for Dialachemist are:

Dialachemist Ltd
4 Petre Road, Clayton Business Park, Clayton Le Moors, Accrington, Lancashire BB5 5JB
Freephone: 0800 008 6366
Email: info@dialachemist.com
Website: www.dialachemist.com

Although Dialachemist provide free delivery, you may still be liable for the prescription charge unless you have a Medical Exemption Certificate. You can find out more about prescription costs and exemption on Information sheet 22A - Benefits and entitlements (see Further information at the end of this sheet to access other publications).

References


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McDermott CJ and Shaw PJ, Diagnosis and management of motor neurone disease bmj.com 2008 vol 336
Medline (online information), a service of the U.S. National Library of Medicine, NIH National Institutes of Health, August 2013, search for riluzole at: www.nlm.nih.gov


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Further information

If you would like to find out more about clinical trials, search for treatment trials on our website at www.mndassociation.org

You may find these publications from the MND Association helpful:

- Research information sheet C– *Unproven treatments and motor neurone disease*
- Information Sheet 16 – *MND Care Centre programme*
- Information sheet 22A - *Benefits and entitlements*
- *Living with motor neurone disease* – our guide to help people manage everyday life with MND

If you have any questions about the information on this sheet, please contact the MND Connect team.

Downloads of all our information sheets and most of our publications are available from our website. You can also order our publications direct from the MND Connect team, who will also be able to advise on individual needs:
We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25
Or request a paper version by email: infofeedback@mndassociation.org

Or write to:
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