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Riluzole

Information for people with or affected by Motor Neurone Disease (MND)

If you have been diagnosed with MND, you may be thinking about taking riluzole. Approved for use in the UK, this drug can help slow the progress of the disease, but the benefit is limited. This information sheet explains how riluzole works, its possible side effects and how it is prescribed. The content includes:

1. What is riluzole?
2. Where can I get riluzole?
3. What else can I do?
4. How do I find out more?



This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5
How do I find out more?

1. What is riluzole?

Riluzole is a 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 available on the NHS 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 is usually managed by GPs. This is done under an agreement known as a shared care arrangement between the GP and the neurological specialist.

Riluzole is not necessarily prescribed in every case of MND. For example, it may not be suitable for primary lateral sclerosis (PLS), a form of MND that is typically slower to progress. This needs to be discussed with the consultant making the assessment.

Other drugs to treat MND are likely to become approved in the UK. We will update this sheet as soon as any new drug is available through prescription.

How does riluzole work?

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 with the release of a chemical messenger. For many motor neurones this messenger is a chemical called glutamate, but high concentrations of glutamate can be toxic to neurones. 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.

What are the benefits of riluzole?

This drug may slow down the progression of the disease and increase survival by several months. However, riluzole is not a cure. It will not reverse damage to motor neurones which have already been affected.

Although riluzole cannot reverse the effects of MND, taking it as soon as possible after diagnosis will give you the most benefit.

In the clinical trials for riluzole, 1477 people participated, including those from a number of UK centres. They all had amyotrophic lateral sclerosis (ALS), the most common form of MND. The randomised controlled trials compared those taking riluzole with a control group taking a placebo. These original trials had a fixed end date (18 months) and people over 75 were not included.

Since then, research suggests long term benefits from riluzole could be better than initially thought.

However, it is not possible to predict how riluzole will benefit any one individual, as MND progresses differently for each person. Some people with MND also report a positive effect on their psychological wellbeing, by taking a drug that may help extend survival.

Some clinical trials may need people with MND to be taking riluzole.



See more about research and clinical trials at:
mndassociation.org/research

How is riluzole taken?

Riluzole comes in tablet form, or in a liquid form if you have swallowing difficulties. You can also get a film that you place on the tongue, which slowly dissolves (known as orodispersible film).

Ask your health and social care team for the most suitable way to take the medication - the liquid form may be helpful if you need to take medication through a feeding tube.

Several brands of riluzole are available, which may have differences, such as thickness of tablet coating or the way that you take the medication. However, they all contain the same active ingredient.

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).

You may wish to review your use of riluzole if it is difficult to take or if you have side effects, or in the later stages of MND. Ask your specialist for guidance before making any changes.

What are the side effects?

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

- nausea and 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).

Coughing and breathing problems may be related directly to MND. See your consultant if you get signs of any related symptoms.

Side effects are not generally serious and can be improved by reducing or stopping the riluzole dosage under medical supervision. There are no known side effects if riluzole is discontinued gradually or abruptly.

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

Riluzole is not recommended:

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

It is highly unlikely that riluzole interacts with any other medication, but discuss any other medication you are taking with your prescribing doctor.

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.”

If you wish to take part in a clinical trial, you may need to have been taking riluzole. This is something to think about when first discussing riluzole with your neurologist.



See more about research and clinical trials at:
mndassociation.org/research

Some people question whether the moderate benefit extends survival in a positive way or if prolonging life will impact too much on quality of life as the symptoms progress. 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.”

Your consultant may be able to help you make an informed decision about the drug, to suit your needs and preferences.

2. Where can I get riluzole?

If your consultant thinks that riluzole would be suitable for you, and you decide to take it, the drug will be prescribed. This is usually initiated by your neurologist, managed by your GP and delivered through 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 for riluzole resulted in a recommendation by NICE for the drug 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 are aware of 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.

3. What else can I do?

There is no drug alternative to riluzole yet in the UK but other drugs are progressing through trials and approvals.

If you decide not to use or stop taking riluzole for any reason, you may notice a very slight difference in progression. However, there are other ways to take positive action to 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 and assessment of swallowing difficulties with a speech and language therapist
- 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.”



Find our resources on symptom control and support using our Care information finder at: **mndassociation.org/careinfofinder**

Seeking help and discussing options with your health and social care team may provide a more positive pathway through the disease progression.



“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.

Co-ordinated care

It is recommended that a co-ordinated 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 gives support beyond immediate primary healthcare for 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.

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 an early referral can be beneficial. There may be a waiting period before you can access a palliative care team.



See our booklet: **Types of care.**

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.

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.

There are many combinations of assistance and a multidisciplinary team is comprised of specialist health and social care professionals. Depending on your needs, your multidisciplinary support may include a:

- neurologist
- clinical nurse specialist
- physiotherapist
- occupational therapist
- dietitian
- speech and language therapist
- respiratory management team
- care centre co-ordinator (or MND specialist co-ordinator, sometimes found in other neurological services)
- specialist in palliative care.

4. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Government information

Online government information about benefits and support. in.

Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website: **nhs.uk**

Tel: 111 (for urgent medical advice in England, available 24/7)
Website: **111.nhs.uk** (For England)

Tel: 111 (for urgent medical advice in Wales, available 24/7)
Website: **111.wales.nhs.uk** (For Wales)

Tel: Find individual trusts in Northern Ireland on website contact page
Website: **hscni.net** (For Northern Ireland)

Tel: 111 (for urgent medical advice, available 24/7)
Website: **nhs24.scot** (For Scotland)

NI Direct

Provides government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page
Website: **nidirect.gov.uk**

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References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A NICE guideline on Motor Neurone Disease
- 3A MND care centres and networks
- 10A Benefits and entitlements

Research information sheet C - Unproven treatments in MND.

Booklets

Caring and MND - quick guide
Types of care
What you should expect from your care

Large guides

Living with MND
Caring and MND - support for you

Search for information by need at: **mndassociation.org/careinfofinder**
Find information for professionals at: **mndassociation.org/professionals**
Download our information at: **mndassociation.org/publications**
Find information in other languages at: **mndassociation.org/languages**
Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: **mndassociation.org/our-services**

Local and regional support

Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**

Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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