



5A

Riluzole

Information for people with or affected by motor neurone disease

If you have been diagnosed with MND, you may be thinking about taking the drug riluzole. This sheet explains how it can help and possible side effects. Although the benefits are limited, it is important to understand how the drug is provided.

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.

The content includes the following sections:

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



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.



This symbol is used to highlight **quotes** from other people with or affected by MND.

This information has been evidenced, user tested and reviewed by experts.

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 may be managed by GPs, under an agreement known as a shared care arrangement with the specialist.

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

Other drugs for the treatment of MND are beginning to emerge in the UK. We will update this sheet as soon as any new drug is approved and 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 via the release of a chemical messenger. For many motor neurones this chemical 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.

Taking Riluzole as soon as possible after diagnosis will not reverse the effects of MND, but 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 type 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.

Please note: Some clinical trials may need people with MND to be taking riluzole (see *Further information* in section 4: *How do I find out more?* for more information).

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.

Different brands of riluzole are available, which may have differing ingredients or levels of ingredient, such as thickness of tablet coating, but they will always 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).

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.

What are the 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).

Please note: some people may have coughing and breathing problems related directly to MND, so please see your consultant should any relevant symptoms occur.

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 (see later heading *What else can I do?*).

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 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. However, do discuss any other medication you are taking with the 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.”

Taking Riluzole may also be required for taking part in some clinical trials, if this is something you wish to consider. See *Further information* in section 4: *How do I find out more?* for more detail.

Some people 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.”

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 recommends that riluzole would be suitable for you, and you decide to take it, the drug is available by prescription (usually from your neurologist and continued by 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 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.

If you decide not to use this drug or if you have to stop taking it 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
- 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.”

We provide a wide range of information on symptom management, interventions, therapies and ways to manage the symptoms of MND:

www.mndassociation.org/careinfo

Seeking help and discussing options with your health and social care team may provide a more positive pathway through the disease progression (see next heading *Co-ordinated care*).

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 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 an 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.

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.



For more details about this support, see:
Information sheet 3A - *MND care centres and networks*

There are many combinations of assistance and a multidisciplinary team is comprised of specialist health and social care professionals.

Among others, 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, which is sometimes found in other neurological services)
- specialist in palliative care
- MND Association visitor
- regional MND Association staff member.

4: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

GOV.UK

Online government advice on a variety of welfare topics, including support for people with disabilities.

Email: email addresses are provided on the website, related to each enquiry
Website: **www.gov.uk**
www.nidirect.gov.uk (Northern Ireland)

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards. This is an online information service only (see also NHS Direct Wales).

Email: through the website contact page
Website: **www.nhs.wales**

MND Scotland

MND Scotland provides care, information and research funding for people affected by motor neurone disease in Scotland.

Address: 6th floor, Merchant Exchange, 20 Bell Street, Glasgow,
G1 1LG

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website : www.mndscotland.org.uk

NHS UK

The main online reference for the NHS

Website: www.nhs.uk

NHS 111

The NHS online/telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111

NHS 111 Wales

Health advice and information service for Wales.

Telephone: 111

Website: <https://111.wales.nhs.uk>

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page

Website: www.hscni.net

NI Direct

Providing 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: www.nidirect.gov.uk

References

References used to support this information are available on request from:

Email: infofeedback@mndassociation.org

or write to:

Care Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

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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 information sheets from the MND Association helpful:

1A – *About the NICE guideline on motor neurone disease*

3A – *MND care centres and networks*

10A – *Benefits and entitlements*

Research information sheet C – *Unproven treatments in MND*

We also provide the following guides:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – a summary of our information for carers

You can download most of our publications from our website at: **www.mndassociation.org/publications** or order in print from the MND Connect helpline, who can provide further information and support. MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through the website

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 or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:
www.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, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

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