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Riluzole

Information for people with or affected by motor neurone disease

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.

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?**

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.

 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 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.

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 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 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.

What are the benefits of riluzole?

Riluzole is not a cure, and will not reverse any damage to the motor neurones already affected. After 12-18 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 (with 1477 participants across 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* in section 4: *How do I find out more?* for more information).

How is riluzole 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, or in a liquid form if you have swallowing difficulties. Ask your health and social care team for advice on the most suitable way to take the medication. Different brands of riluzole are available, which may have differing ingredients or levels of ingredient, eg thickness of tablet coating.

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).

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?*).

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.

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 qualify you for certain 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).

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.

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, 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* in section 4: *How can I find out more?* for contact details.

3: What else can I do?

There is no drug alternative yet to riluzole in the UK. 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 information sheets provide a wide range of guidance on symptom management, interventions, therapies and ways to manage its impact where possible.

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 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 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
- 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.

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*

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.wales.nhs.uk

MND Scotland

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

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

NHS Choices

The main online reference for the NHS, including information on continuing healthcare.

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 Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647
Website: www.nhsdirect.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, PO Box 246, Northampton NN1 2PR

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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 – the summary version 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, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: www.mndassociation.org

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

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.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, PO Box 246 Northampton NN1 2PR



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