

**Guidance on
the Use of
Riluzole
(Rilutek) for the
Treatment of
Motor Neurone
Disease -
Information for
Patients**

January 2001

the NHS Direct website
(www.nhsdirect.nhs.uk) and
search for Motor Neurone
Disease.

Yes. The guidance will be
reviewed in January 2004.

Will NICE review
its Guidance?

**Further
Information**

Further information on NICE,
and the full guidance issued to
the NHS is available on the
NICE web site
(www.nice.org.uk). It can also
be requested from 0541 555
455, quoting reference 23071.

This leaflet is also available
in Welsh, (Ref no 23074).

**Mae'r daflen hon hefyd ar
gael yn Gymraeg (rhif
cyfeirnod 23074).**

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What is NICE Guidance?

The National Institute for Clinical Excellence (NICE) is a part of the NHS. It produces guidance for both the NHS and patients on medicines, medical equipment, diagnostic tests and clinical & surgical procedures and where they should be used.

When the Institute evaluates these things, it is called an appraisal. Each appraisal takes around 12 months to complete and involves the manufacturers of the drug or device, the professional organisations and the groups who represent patients.

NICE was asked to look at the available evidence on riluzole (Rilutek) and provide guidance that would help the NHS in England and Wales decide where it should be used in the treatment of Motor Neurone Disease.

Motor Neurone Disease (MND) is the name given to a group of diseases that affect the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells along which the brain sends instructions, in the form of electrical impulses, to the muscles.

What is Motor Neurone Disease?

Deterioration of these cells leads to weakness and wasting of muscles. In the majority of cases the symptoms first occur in the arms and legs. Some people may develop weakness and wasting in the muscles supplying the face and throat, causing problems with speech and difficulty chewing and swallowing.

MND does not affect touch, taste, sight, smell or hearing, nor directly bladder, bowel, or sexual function. In the vast majority of cases, the intellect remains unaffected.

MND is generally a progressive disease and the rate of progression can vary greatly from one person to another.

Amyotrophic lateral sclerosis (ALS) is the most common form of MND, accounting for up to 8 out of 10 of all cases.

People with MND do not get better and most people with MND die within approximately 3 years of the onset of symptoms. Most people with MND eventually pass through a phase which is characteristic of ALS.

What is riluzole (Rilutek)?

Riluzole (Rilutek) is a medicine that can be used to treat some forms of Motor Neurone Disease. Although it is not a cure, research has shown that it can prolong survival. The prescription of riluzole should only be started by a specialist who has experience in the management of MND.

What has NICE recommended about the use of riluzole?

NICE has recommended to the NHS that riluzole should be available for the treatment of individuals with MND in accordance with its licensed indications.

Treatment with riluzole should only be started by a neurological specialist who is experienced in the management of MND. Routine supervision of therapy may be managed by general practitioners, but this should be under an agreement known as a shared care arrangement with the specialist.

What should I do?

If you, or someone you care for has Motor Neurone Disease, you might want to discuss this guidance with your GP or neurologist. If you have access to the Internet and would like to find out more about MND visit