MND Association

What you should expect from your care

For people with Motor Neurone Disease (MND), their carers and families.

Every day, being able to access appropriate treatment and care with motor neurone disease matters.

“The content of this pocket guide accurately reflects recommendations in the NICE guideline on motor neurone disease. It also supports statements 1, 2, 3 and 5 in the NICE quality standard for motor neurone disease.”

National Institute for Health and Care Excellence, November 2018. (Statement checked at last revision September 2024.)

See the NICE guideline for motor neurone disease at
nice.org.uk/guidance/ng42

See the NICE quality standard for motor neurone disease at
nice.org.uk/guidance/qs126

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piftick.org.uk

Use this handy quick guide to open discussions about your care with health and social care professionals and providers.

This may help you access suitable support.

The information here is taken from the NICE guideline on MND, which provides recommendations about appropriate treatment and care. NICE stands for National Institute for Health and Care Excellence.

See more in our information sheet **1A About the NICE guideline on Motor Neurone Disease**

Find our information sheets at **mndassociation.org/careinfo**

The pages that follow highlight the recommendations in the guidelines but you are unlikely to need all of these at once.

Use the questions provided to help you discuss needs as they arise and plan ahead for future care.

Diagnosis

1

Have you been:

- Offered a follow-up appointment with a neurologist?
- Offered information and support?
- Referred for assessment with adult social care services, if needed?

A drug called riluzole may help to slow the progress of MND, by a few months. It is not covered in the NICE guideline on MND, but has been recommended for use with the disease by NICE.

For more information, see
mndassociation.org/riluzole

Organising your care

2

Have you been:

- Given a contact for a specialist MND or neurological service?
- Offered regular co-ordinated assessments of your symptoms and needs, to help ensure your care is both consistent and reviewed?
- Asked about your individual needs relating to the management of your symptoms?

Psychological and social support

3

Have you been:

- Asked about the thoughts and feelings you, your carers and family have about MND?
- Informed about how to access emotional support, or guidance on sexuality and intimacy if needed?
- Informed about how your carers and family can access support, including respite, taking a break and their right to a carer’s assessment?

Thinking and behaviour

4

Have you been:

- Asked about any changes to your thinking and behaviour?
- Referred for formal assessment if wished or needed?

Muscle problems and exercise

5

Have you been:

- Given an opportunity to discuss exercise programmes to help with joint pain, stiffness and flexibility?
- Reviewed to check whether any recommended exercise or physical therapy is meeting your needs?
- Given an opportunity to discuss medication to help with any cramps, stiffness or pain?

Equipment and adaptations

6

Have you been:

- Assessed for daily living needs, such as shopping, meals, household tasks or personal care?
- Assessed for equipment and home adaptations to meet your current and potential future needs?
- Referred to a wheelchair service, if needed?

Communication

7

Have you been:

- Assessed by a speech and language therapist for your communication needs, or reviewed if your needs have changed?
- Referred for further assessment if you need communication aids?
- Given help to ensure any communication aids work well with other assistive equipment you may use?

Nutrition

8

Have you been:

- Monitored for your weight?
- Assessed for any swallowing, eating or drinking difficulties?
- Given an opportunity to discuss alternative ways to receive nutrition, such as tube feeding?

Saliva

9

Have you been:

- Assessed if you have any problems with saliva?
- Recommended support, treatment options or medicine for any saliva problems?

Breathing

10

Have you been:

- Assessed for any breathing difficulties?
- Offered support and information to recognise and manage breathlessness?

Non-invasive ventilation (NIV)

11

Have you been:

- Given an opportunity to discuss use of non-invasive ventilation (NIV) and offered a trial of this if you have breathing problems?
- Informed about the advantages and disadvantages of this support, and what to expect if you wish to withdraw this in the future?
- Informed about other support options to help breathing problems?

Coughing

12

Have you been:

- Shown how breathing exercises and techniques can help to improve the strength of your cough, if needed?
- Offered support through the use of a machine to help you cough, if needed?

Planning ahead

13

Have you been:

- Offered an opportunity to discuss future care, plans and concerns about end of life, if wished?
- Given support and advice about planning ahead for future care?
- Given prompt access to specialist palliative care services, if needed?

What can I do if my needs are not being met?

If you do not receive the care or treatment you need, or have any problems, discuss first with the relevant health or social care professional, or provider.

If this does not improve the situation, make a formal complaint or appeal to the service involved. They should be able to provide information or advise how to do this.

See more about making formal appeals and complaints at **mndassociation.org/mycare**

If you need further help, support or would like to order our publications, contact our MND Connect helpline:

Tel: 0808 8026262 or Email:

mndconnect@mndassociation.org

See our other publications at
mndassociation.org/publications

Search for resources by need at
mndassociation.org/careinfofinder

We welcome your feedback about this booklet at:

smartsurvey.co.uk/s/NICEguide

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