

Motor neurone disease checklist

To help you manage your
condition and think ahead



Motor neurone disease checklist

With MND, your needs change over time and you may be at risk of a fall, a chest infection or other problems caused by your symptoms. This checklist is designed to help you to think about your wellbeing and the support you may need. If you know what to watch out for, you can plan ahead more effectively.

If you answer yes to a question, the suggestions provided may help. You can also find a wide range of information about MND treatment and care at:

www.mndassociation.org/publications

Use the personal action plan at the end of the checklist to note any concerns and keep the completed form. You can use this at appointments with health and social care professionals, who can advise with your circumstances in mind.

Please do not return it to the MND Association, thank you.

If you have any queries, or would like to order our publications, contact our MND Connect helpline:

mndconnect

0808 802 6262

mndconnect@mndassociation.org



To help you manage your condition and think ahead

Daily living

1

Do you need help with any daily tasks at home (such as dressing, preparing food or personal hygiene)?

yes

no

- Is there anyone who can provide that support? Keep contact details in or near your telephone.
- If not, have you had a needs assessment to see if you need care services? (*Ask for an appointment with your local authority, or your health and social care trust in Northern Ireland.*)
- Keep contact details for professional care workers in or near your telephone.
- If someone is already supporting you, have they had their own needs assessed as a carer?
- How would you manage if the person supporting you was unable to help you for any reason?

2

Do you receive help with shopping for groceries or supplies?

yes

no

- Is there anyone else who can do this if your usual helper is unwell or unable to support? Keep contact details in or near your telephone.
- Are you able to order groceries or supplies from a supermarket online, with home delivery?
- Do you need help to order online and who could do this?

Getting around

3

Have you had any falls or stumbles over the past few weeks or months?

yes no

- Ask your GP or occupational therapist about personal alarm systems in case you are alone and need urgent help.
- Ask for an assessment by an occupational therapist and a physiotherapist to advise on walking aids, helpful changes to your home environment and how to manage falls if they happen.

4

Do you rely on a walking aid, such as a stick or frame to get around?

yes no

- Check your walking aid is in good condition. For example, if the rubber stops at the bottom have worn, they may slip.

5

Do you feel unsafe or at risk when using your walking aid?

yes no

- Ask for an assessment by an occupational therapist and a physiotherapist who can review your needs and suggest other mobility aids.

6

Do you receive help from someone else when you go out?

yes no

- How would you manage if the person supporting you was unable to help you for any reason?
- Is there anyone else who can provide that support? Keep contact details in or near your telephone.
- Keep contact details in or near your telephone of taxi firms that can help people with disabilities.
- Apply for a Blue Badge through your local authority, or in Northern Ireland through your local health and social care trust. This may help you or the person driving you to park closer to your destination.

7

Do you need help to transfer, for example from bed to chair?

yes no

- Ask for an assessment by a professional, such as a physiotherapist or occupational therapist. They may suggest the use of a hoist or other equipment to help carers move you safely.

Eating and drinking

8

Do you have swallowing difficulties or problems with saliva and coughing that affect how you eat and drink?

yes no

- Ask for an assessment by a speech and language therapist, who can advise on swallowing techniques, and consistencies of food and drink.
- Ask your dietitian about a calorie-rich diet and supplements to help maintain weight. They may also be able to advise on suitable meals by home delivery.
- Ask your dietitian, speech and language therapist and specialist team for advice on tube feeding to top-up or replace meals if needed. (It is best to consider this before you lose a significant amount of weight.)

Breathing

9

Is your breathing affected by MND?

yes no

- You may be vulnerable to chest infections. Try to avoid being with people who have cold or flu symptoms.
- Good hand hygiene can help avoid infection. Keep an alcohol hand cleanser nearby for you and your carers.
- If you use a nebuliser, you may want to keep a spare in case your existing device has any problems. (A nebuliser is a device producing a fine spray that can be inhaled.)
- Have you discussed breathing therapies or the use of ventilation with a respiratory team? Ask your GP for a referral.

10

Do you use non-invasive or invasive ventilation to help you breathe?

yes no

- If you rely on your ventilator, ensure you have spare batteries or back-up power in case of a power cut.
- Keep contact details for your respiratory team and for service maintenance in or near your phone. Ensure your carers have these details too.

Medicines

11

Does someone fetch your prescription medicines from the pharmacist?

yes no

- Is there anyone else who can do this if your usual helper is unwell or unable to support? Keep contact details in or near your telephone.
- Does your local pharmacy provide a home delivery service? Keep their contact details in or near your telephone.
- Do you know how to get replacement medication if you run out?
- If you collect riluzole as a prescription, you may prefer to use the home delivery service through Dialachemist, which has been negotiated by the MND Association.

12

Would it help to keep a stock of over-the-counter remedies?

yes no

- Ask your pharmacist or health and social care team to advise.
- Regularly check that all medicines are within their use-by date.

13

Would you like to keep a first aid kit at home?

yes no

- Ask your pharmacist or health and social care team to advise what this should contain.

14

Would you consider having a flu jab to help protect against flu?

yes no

- You and your carer are entitled to a free flu jab at your GP surgery, from September each year.

15

Would you consider having a vaccine to help protect against pneumonia?

yes no

- With a long-term health condition, you can ask for a single one-off pneumonia vaccination (it may be repeated every five years, depending on the condition). Your GP can advise.

16

Do you ever feel breathless, anxious or experience mild or severe choking?

yes no

- Consider asking your GP to order one of our MND Just in Case kits. They will then prescribe medications for you to keep in the box at home. These can be used in urgent situations by your carer or a healthcare professional, as appropriate. Contact our MND Connect helpline for guidance.

Other

17

Do you have speech and communication difficulties that make it harder to explain your needs?

yes no

- Ask for an assessment by a speech and language therapist who can suggest therapies and communication aids to suit you.
- If you use an electronic communication aid, keep a simple aid nearby (such as an alphabet board) in case of power failure.
- If you already use communication aids, have your needs been reviewed to see if anything should change?

18

Can you think of anything that may increase your risk of hospital admission, such as other conditions?

yes no

- If you have any other concerns about your general health or personal circumstances, discuss these with your health and social care team. They may be able to advise or direct you to support.
- You may find it useful to complete our *Understanding My Needs* form. This personal record can help care workers and hospital staff provide you with suitable treatment and care. Contact our MND Connect helpline for guidance (see page 1).

19

Would you like to have the support of a specialist palliative care or hospice team to help you maintain quality of life and manage your symptoms?

yes no

- Ask your GP or health and social care team for a referral to a specialist palliative care or hospice team. They can help manage your symptoms, which may help to avoid hospital admission or make hospital stays shorter.

20

Would you like to have advance plans in place to ensure future treatment and care happen in the way you prefer?

yes no

- Ask your GP and health and social care team for information about advance care planning and what it means to make an advance decision to refuse treatment (ADRT). If you become unable to communicate or make decisions for yourself, these documents can help guide everyone involved in your care.

Personal action plan

It may help to list any concerns you have identified and actions you could take to prevent problems happening. If you need help with these, ask the health and social care professionals who support you for advice.

My concerns

Actions that may help

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We welcome your views

The MND Association encourages feedback about any aspect of the information we produce. If you would like to provide feedback about this *Motor neurone disease checklist* please use our online form at:

www.surveymonkey.co.uk/r/MNDchecklist

or email: **infofeedback@mndassociation.org**

or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

References

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

Email: **infofeedback@mndassociation.org**

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Acknowledgements

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Birmingham MND Care Centre

Further information

We can help you find out more about MND at the MND Association. Our MND Connect helpline is for professionals as well as people with or affected by the disease. The helpline team can provide information, direct you to our national and regional services, and to other organisations as appropriate.

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You can find a wide range of information for people with or affected by MND at: **www.mndassociation.org/publications**

More information for professionals is available at: **www.mndassociation.org/professionals** including information for care workers and staff working in emergency and acute care. You can also visit our Professionals' forum: **<http://proforum.mndassociation.org>** Information for professionals is available at: **www.mndassociation.org/professionals**

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