

Motor neurone disease checklist

To help you manage your
condition and think ahead



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

At appointments, use the following questions, suggestions and action plan to help discussions with your health and social care professionals. There may be more to explore, depending on your needs. Find this checklist online at: www.mndassociation.org/mndchecklist

Your completed form is yours to keep. Please do not return it to the MND Association, thank you.

If you have a question or need to order any of our printed publications, contact our MND Connect helpline:

mndconnect
0808 802 6262
mndconnect@mndassociation.org

Daily living

1 Do you need any help with personal care (such as washing, dressing or preparing food)? yes ☐ no ☐

Yes

- Is there anyone who can provide that support?
- Ask to have your needs assessed through your local authority or council in England, Wales or Scotland. In Northern Ireland, ask to be assessed through your local health and social care trust.
- See our *Personal care* booklet and guidance at www.mndassociation.org/personalcare
- Keep contact details for helpers and care workers, in or near your telephone.
- If you or your carer have questions, ask your health or social care team for support.
- Find resources to help if you have any dependent children or young people at: www.mndassociation.org/cyp

No

- If someone is supporting you, they can ask their local adult social care team for a carer's assessment.
- How would you manage if the person supporting you was unable to help you for any reason?
- Find guidance for your carers and family members at: www.mndassociation.org/carers or contact our MND Connect helpline.

2 Do you need help with shopping for groceries or supplies? yes ☐ no ☐

Yes

- Are you able to order groceries or supplies online, with home delivery?
- Is there anyone who can pick up supplies or help you order online?
- Volunteer support may be available. Ask your local authority or council in England, Wales or Scotland. In Northern Ireland, ask your local health and social care trust.
- Keep helpful contact details in or near your telephone.

No

- If your usual helper is unable to assist, is there anyone else who can do this?

3 Do you need any financial or social care support? yes ☐ no ☐

Yes

- For guidance on benefits, financial support and cost of living, see www.mndassociation.org/benefits
- Find our Benefits advice service to help you identify and make claims at: www.mndassociation.org/benefitsadvice
- See our services, including our MND Connect helpline, equipment loans, financial support grants and more at: www.mndassociation.org/support-and-information
- For information about social care see www.mndassociation.org/myneeds and our animation about social care at: www.mndassociation.org/animations

No

- If your circumstances change, ask your local adult social care team for guidance, or contact our MND Connect helpline.

“ We have been using the MND Checklist and every patient independently told us how useful, easy to use and helpful it has been... We’ve noticed that some even bring questions written in the back, which has helped us guide that person’s clinic appointment.”

Anthony Hanratty, Advanced Nurse Specialist – Middlesbrough MND Care Centre

Getting around

4 Have you had any recent falls or stumbles?

yes	no
☐	☐

Yes

- Ask a member of your healthcare team 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 again.
- Ask your occupational therapist and physiotherapist to advise your carer on how to help, in a way that is safe for you and them.

No

- Ensure your home is free of trip hazards.
- Find tips about safety at home at: www.mndassociation.org/safety

5 Do you need a walking aid, such as a stick or frame to get around?

yes	no
☐	☐

Yes

- Ask a member of your healthcare team for a referral to a physiotherapist for an assessment of your needs.
- Ask a member of your healthcare team for a referral to an occupational therapist to assess your home environment for any adaptations.
- Check that your walking aid is in good condition. For example, if the rubber stops at the bottom have worn, they may slip.
- If you feel unsafe using your walking aid, ask your physiotherapist for a review.

No

- Find guidance at: www.mndassociation.org/mobility which includes our information sheet 6A - *Physiotherapy* for guidance on maintaining strength and flexibility for as long as possible.

6 Do you need help from someone else to go out or to transfer, for example from bed to chair?

yes	no
☐	☐

Yes

- Keep contact details in or near your telephone of helpers, local drivers or taxi firms that can help disabled people.
- Apply for a Blue Badge to park closer to your destination at: www.gov.uk/apply-blue-badge for England, Wales and Scotland. In Northern Ireland apply at: www.nidirect.gov.uk/services/apply-or-renew-blue-badge-online
- See guidance on travel and transport at: www.mndassociation.org/mobility including our *Getting around* booklet.
- If you have any questions on travel insurance, contact our MND Connect helpline.
- Ask a member of your healthcare team for a referral to a physiotherapist or occupational therapist to assess your needs. They may suggest the use of a hoist or other equipment to help carers move you safely.

No

- If the person supporting you is unable to help for any reason, is there anyone else who can provide that support?
- To think about future needs, see: www.mndassociation.org/mobility including information sheet 11C - *Equipment and wheelchairs*.

7 Do you need help with exercise or physiotherapy?

yes	no
☐	☐

Yes

- Ask your GP or a member of your healthcare team for referral to a physiotherapist for assessment and guidance.
- Ask your physiotherapist how assisted exercise can help with range of movement and flexibility.
- Ask your physiotherapist about ways to manage your energy levels when exercising.
- Find guidance at: www.mndassociation.org/mobility which includes our information sheet 6A - *Physiotherapy*.

No

- If your needs change, you can ask to be referred to a physiotherapist at any time.

Speech and communication

8

Do you need help with your speech and communication?

yes

no

☐☐

Yes

- Ask a member of your healthcare team for referral to a speech and language therapist, who can assess your needs and suggest therapies and communication aids to suit you.
- See our resources to help at: www.mndassociation.org/speech or find our Communication aids service at: www.mndassociation.org/communicationaids
- If you use an electronic communication aid, keep a simple aid nearby (such as an alphabet board) in case of power failure.
- If you need translated information see: www.mndassociation.org/languages
- Find resources to help communicate with dependent children or young people at: www.mndassociation.org/cyp

No

- If you already use communication aids, have your needs been reviewed to see if anything should change?

9

Would you like to bank your recorded voice for use on a communication aid?

yes

no

☐☐

Yes

- Ask a member of your healthcare team for a referral to a speech and language therapist for guidance.
- See our Communication aids service at: www.mndassociation.org/communicationaids
- Find our animation on voice banking and message banking at: www.mndassociation.org/animations

No

- If you don't want to use voice banking to use your voice on a communication aid, you can still record specific messages to use at a later date.

Eating and drinking

10

Do you have any problems with swallowing, saliva and coughing, that affect how you eat and drink?

yes

no

☐☐

Yes

- Ask a member of your healthcare team for a referral to a speech and language therapist, who can advise on swallowing techniques, and consistencies of food and drink.
- Ask a member of your healthcare team for a referral to a dietitian, who can advise 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 a member of your healthcare team about liquid medications or patches if you find it difficult to swallow tablets.
- For guidance, see: www.mndassociation.org/eating including our *Eating and drinking* guide and web app, with information and easy swallow recipes.

No

- For guidance, see: www.mndassociation.org/eating if you start to get any problems with swallowing, saliva or coughing.

11

Would you like to find out more about tube feeding?

yes

no

☐☐

Yes

- Ask your dietitian, speech and language therapist and healthcare team for advice on tube feeding to top-up or replace meals.
- Find all our resources about tube feeding and decision making at: www.mndassociation.org/eating

No

- If your views change, you can always ask your healthcare team about tube feeding at a later date. It is best to consider this before you lose a significant amount of weight.

Symptom care and medicines

12 Do you need help to ease any symptoms?

yes	no
☐	☐

Yes

- Find out about types of care to help with MND at: www.mndassociation.org/caretypes
- Ask a member of your healthcare team for guidance or referrals to specialists, or an MND care centre or network.
- See more about getting the right treatment or care with MND at: www.mndassociation.org/mycare including our pocket guide *What you should expect from your care*. This can help at appointments and is based on the NICE guideline for the management of MND.
- MND does not usually cause pain directly, but you may get pain from some of the symptoms. Find our information sheet range at: www.mndassociation.org/careinfo including 6C - *Managing pain*.
- If your symptoms are caused by Kennedy's disease see our support pages for this condition at: www.mndassociation.org/kennedys

No

- If you get any future symptoms, see our information sheet range at: www.mndassociation.org/careinfo or search by need using our *Care information finder* at: www.mndassociation.org/careinfofinder

13 Would you like to discuss any aspect of your emotional wellbeing?

yes	no
☐	☐

Yes

- Ask your health and social care team for support on any aspect of emotional health.
- For guidance and information resources on emotions, thinking or behaviour, see www.mndassociation.org/emotions
- Our booklet on *Sex and relationships* may be helpful if you have questions about intimacy, whether you are with a partner or single.

No

- If you need support in the future, find guidance at: www.mndassociation.org/emotions

14 Would you like to find out more about the drug riluzole for use with MND?

yes	no
☐	☐

Yes

- Riluzole may moderately slow the progression of the disease, where suitable. Ask a member of your healthcare team for a referral to a neurologist for assessment and guidance.
- If you are prescribed riluzole for MND, home delivery may be available through a local or online pharmacy.
- See our information sheets at: www.mndassociation.org/careinfo including 5A - *Riluzole*.

No

- Other drugs for the treatment of MND are emerging. As soon as they become available on prescription, we will update our resources.

15 Would you like to find out about flu jabs, vaccines or getting medicines delivered?

yes	no
☐	☐

Yes

- You and your carer are entitled to a free flu jab at your GP surgery, from September each year. With a long-term health condition, you can also ask for a single one-off pneumonia vaccination (it may be repeated every five years, depending on the condition). Your GP or healthcare team can advise, including latest guidance about covid vaccines.
- Ask your local pharmacy if they provide a home delivery service. Prescriptions are free in Wales, Northern Ireland and Scotland. You may also be exempt from prescription charges in England - ask your GP.
- Ask a member of your healthcare team for the best way to get your prescriptions repeated, reviewed or replaced.
- You can get over the counter remedies and first aid kits delivered by a supermarket.
- Regularly check that all medicines are within their use-by date.

No

- If someone picks up your medication for you, do you have a backup if they are unable to help? Keep contact details in or near your telephone.
- Not all symptoms may be due to MND. Ask a member of your healthcare team for guidance if you get any new symptoms.

Breathing

16 Is your breathing affected by MND?

yes ☐ no ☐

Yes

- Have you had your breathing assessed by a respiratory team? Ask a member of your healthcare team for a referral.
- Find guidance at: www.mndassociation.org/breathing including our information sheet 8A - *Support for breathing problems*.
- 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.)

No

- If you get any future symptoms, find guidance at: www.mndassociation.org/breathing

17 Would you like to find out more about assisted ventilation to help you breathe?

yes ☐ no ☐

Yes

- Ask a member of your healthcare team for a referral to a respiratory team for assessment and guidance on ventilation.
- Find information sheets to help with decision making about breathing support at: www.mndassociation.org/breathing
- 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.

No

- If you want to find out more about ventilation in the future, find our resources at: www.mndassociation.org/breathing

Planning ahead

18 Can you think of anything that may increase your risk of hospital admission?

yes ☐ no ☐

Yes

- If you have any concerns about your general health, other conditions or personal circumstances, discuss these with your health and social care team. They can provide guidance or direct you to appropriate support.
- You may find it useful to complete our *Understanding My Needs* form to help care workers and hospital staff support you. See *Forms and resources to help you communicate your needs* at: www.mndassociation.org/careinfo
- If you live in England or Wales, and your health needs have become complex or urgent, you may qualify for NHS Continuing Healthcare (CHC). Find information at: www.mndassociation.org/chc and in 10D – *NHS Continuing Healthcare* in information sheets at: www.mndassociation.org/careinfo or watch our animation at: www.mndassociation.org/animations
Scotland operates a different system called Hospital Based Complex Clinical Care. In Northern Ireland, contact your local health and social care trust to see what is available.

No

- See guidance on ways to avoid risk at: www.mndassociation.org/safety
- Use our *Care information finder* to search for resources by need at: www.mndassociation.org/careinfofinder

19 Would you like support from a hospice or specialist palliative care team to help your quality of life?

yes ☐ no ☐

Yes

- Ask a member of your healthcare team for a referral to a hospice or specialist palliative care team. They can help manage your symptoms, which may help to avoid hospital admission or make hospital stays shorter.
- See information sheets at www.mndassociation.org/careinfo including 3D - *Hospice and palliative care*.

No

- If you change your mind, you can ask for a referral at any point. It can be helpful to ask about this as early as possible in case there is a waiting list.

20

Would you like to plan ahead for preferred future treatment and care?

yes

no

☐

☐

- Yes
- When you feel ready, ask a member of your healthcare team for information about advance care planning.
 - See information sheets at www.mndassociation.org/careinfo including 14A - *Advanced Decisions to Refuse Treatment (ADRT) and advanced care planning*.
 - See *Forms and resources to help communicate your needs* at: www.mndassociation.org/careinfo and ways to plan at: www.mndassociation.org/planningahead
- No
- If you don't feel ready to tackle this yet, you can return at any point to: www.mndassociation.org/planningahead

Further information

Find guidance about MND at: www.mndassociation.org/publications or search for information by need at: www.mndassociation.org/careinfofinder

Our MND Connect helpline can provide information, help you find our services and other organisations as appropriate.

The helpline can also support professionals. They can find our guidance at: www.mndassociation.org/professionals

mndconnect

0808 802 6262

mndconnect@mndassociation.org

Personal action plan

It can help to list any concerns and actions that may help prevent problems. Ask your health and social care professionals for guidance.

My concerns	Actions that may help
1	
2	
3	

My concerns

Actions that may help

4	
5	
7	
8	

We welcome your views

Let us know what you think of this checklist. We'd love to hear what you think we did well and how we can improve the content for people with or affected by MND. Your anonymous comments may also be used to support and influence, as they help us share real MND experience and raise awareness in our resources, campaigns and applications for funding.

Find our online feedback form at: www.smartsurvey.co.uk/s/MNDchecklist
or email: infofeedback@mndassociation.org
or write to: *Information Feedback* at the address shown below.

References

References used to support this information are available on request. Email as shown above or write to *Information Feedback* at the address shown below.

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This information has been evidenced,
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