

3: What do I need to think about?

This section looks at some of the things you may need to consider when diagnosed with MND.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: **www.mndassociation.org/publications**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

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It can take time to accept and adjust to a diagnosis of MND. However, once you know why symptoms are happening, you can look at available options to make informed decisions.

With MND, there is a lot to think about. The following list covers 'things I wish I had known at the start' based on feedback from others affected by the disease.

Not all of these suggestions will apply to your own situation, but they may help you feel more prepared for the challenges ahead. We have also shown which sections of this guide provide further detail.

“ This is the first situation in my life where I can't control the outcome. It's a waiting game to anticipate 'what will happen next'.”

1. Don't rush into purchasing equipment

Before buying equipment or assistive aids, have your needs assessed by a relevant professional, such as an occupational therapist. Equipment may not always suit everyone and mistakes can be costly. You can also get certain items free or on loan through the NHS or social services. Assessment will also consider your future needs. For example, if you plan to install a stairlift and you use a wheelchair, you may need a second wheelchair upstairs and a hoist for transfer.

A through-floor lift or downstairs conversion may provide another option, and funding may be available to help with costs.

See Section 6: *Getting around*, Section 7: *Everyday activities and personal care* and Section 10: *Finance, work and social care*.

2. Seek an assessment of your care needs

Adult social care services can provide a needs assessment for yourself – known as a community care assessment in Northern Ireland – and a carer's assessment for carers. Assessment can help you identify needs, get support and plan for emergencies. Support can vary between regions, so explore what's available during your assessment. These assessments are free, but a financial assessment works out if you need to pay towards agreed services.

See Section 10: *Finance, work and social care*.

3. Provide a full picture of your needs

If you are being assessed for care needs or benefits, give lots of detail when describing how MND affects you. This is important to get appropriate support. Keep a diary, so you can give examples of your symptoms, the support you need and how long tasks take.

See Section 10: *Finance, work and social care*.

4. Check out the benefits system

If you have not accessed benefits before, it may feel uncomfortable and confusing. However, it's important to find out what you may be entitled to – this is your right.

See Section 10: Finance, work and social care and Further information at the end of this section for details about our Benefits Advice Service.

5. Take advice on financial decisions

Try not to rush decisions that could affect finance or work. Seek advice from an independent financial adviser and a benefits adviser. For example, early retirement payments may affect access to certain benefits.

See Section 10: Finance, work and social care.

6. Ask about managing your bank account

Ask your bank for advice on managing your bank account if you feel you may need help to continue doing this. There may be different ways to set up shared access with a spouse, partner or trusted friend.

See Section 10: Finance, work and social care.

7. Think about home adaptations early

As your symptoms progress, you may need to adapt your home for disabled access. This can take time and you may need to seek funding, which can also be a lengthy process. Explore adaptations and funding as soon as you think it may be necessary. An occupational therapist (OT) can help assess your current and possible future needs. This assessment is free, unless arranged with an independent OT who charges.

See Section 6: Getting around.

8. Keep a list of questions and contacts

Keep a list of questions you want to ask at appointments, so you don't miss anything. Note down any answers to read again later. You can also ask to record the conversation – most mobile phones allow you to do this.

See the notes pages at the end of this guide to help you keep track, including the Contact record and the Appointment and communication record.

9. Find out as much as you can about treatments

Ask your health care team as soon as possible about available treatments to manage symptoms. Knowing what each option could mean for you (even before you need it), will help you make informed decisions as symptoms progress. In all cases, the choice is yours, but timing is important for some interventions.


See Section 11: Planning ahead.

10. Find out about voice banking

Over time, you may experience difficulties with speech and communication, but simple aids can help, such as alphabet boards and communication charts. Some high-tech devices use spoken voices, such as communication apps on smartphones, tablets and computers. You can create an electronic version of your own voice by recording a bank of phrases. This can help you preserve a sense of identity and is known as voice banking. For best results, voice banking needs to be completed before any changes to your voice, so explore this option as early as possible if you'd like to consider it. If your voice is already changing, you can ask a family member or friend to record their voice for you, if this feels appropriate.

For example, they may sound similar to you or have the same accent. Ask a speech and language therapist for advice.

See Section 8: *Speech and communication* for more details.



“ It was too late to bank my voice by the time I realised I could.”

11. Have difficult conversations as early as possible

When planning ahead, it may feel difficult to discuss the later stages of MND with your health and social care team, and those close to you. Yet making your wishes known about future care can help guide everyone involved. If your speech and communication are affected, it may be easier to discuss plans earlier rather than later. Some people with MND also experience changes to the way they think and process information, so early conversations can be helpful.

See Section 11: *Planning ahead*.

12. Find out about specialist palliative care and hospice care

Palliative and hospice care is about achieving the best possible quality of life for you and those close to you. This is done by managing symptoms, but also wider emotional, practical or spiritual support, as required. You may not need this support immediately, but ask your GP when a local referral is possible. The earlier you can link in to these services, the more benefit they can bring. Their detailed records of your needs can also help reduce any time spent in hospital.

See Section 11: *Planning ahead*.

13. Help your professionals become more aware about MND

MND isn't common and your health and social care professionals may not always have experience of working with the disease. We provide information, education and support services for professionals. They can find out more at: www.mndassociation.org/professionals or through our MND Connect helpline: **0808 802 6262** or email:

mndconnect@mndassociation.org

Professionals can find recommendations about MND treatment and care in the NICE guideline on MND. The guideline is produced by the National Institute for Health and Care Excellence. Our pocket book *What you should expect from your care* is supplied in the folder with this guide or download at www.mndassociation.org/mycare. You can use the prompts inside this handy guide to ask questions at appointments, based on the NICE guideline.

See Section 2: *Managing symptoms* and Section 10: *Finance, work and social care*.

If you are disabled and need information in a particular format from your health and social care professionals, this should be provided. Let them know your needs. This is now mandatory for NHS and social care services in England – for more details, search for *accessible information standard* at: www.england.nhs.uk.

14. You are not alone

Support from others affected by MND can help reduce any feelings of isolation. Our local branch and group support meetings can be a good way to connect, or you may prefer our online forum, which provides a safe place to share experiences:

<https://forum.mndassociation.org>

Even if this type of support doesn't feel right for you now, you can always explore this at another time.

See Section 12: *How we can help you.*



“ I find it really helpful meeting new friends in the same position as myself, and being able to discuss problems and hear their solutions.”

15. We are here to support you

If you have questions or just need support, contact our MND Connect helpline: **0808 802 6262** or email: **mndconnect@mndassociation.org**

The team can guide you to our information resources, our services (including branches and groups) and external services.

See Section 12: *How we can help you.*

Further information:

From our range of information sheets:

1A: NICE guideline on motor neurone disease

From our guides and other publications:

MND Checklist: a questionnaire that helps you think about your condition and how to plan and prepare for your care needs.

Caring and MND: support for you: a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide: a booklet to help someone new to the caring role.

Information to pass to your health or social care professionals:

Motor neurone disease – a guide for GPs and primary care teams

Download our publications at: **www.mndassociation.org/publications**
Or order them from **MND Connect**, our support and information helpline:
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Email: **mndconnect@mndassociation.org**

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: *How we can help you.*

MND Association Benefits Advice Service:

Our trained advisers can help you identify benefits you may be able to claim if living with MND or Kennedy's disease. This service is provided by Citizens Advice Cardiff and the Vale for England and Wales, or Advice NI for Northern Ireland. The service is available by telephone or email, and there is also a web chat facility for those living in England or Wales. We may be able to arrange for an interpreter to join your call with an adviser if you struggle with English and have nobody to speak on your behalf.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: through this webpage: **www.mndassociation.org/benefitsadvice**

Online forum:

We host this forum for you to share information and support with others affected by MND, **<https://forum.mndassociation.org>**

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MND Association

Francis Crick House (2nd Floor)

6 Summerhouse Road, Moulton Park

Northampton NN3 6BJ

Tel: 01604 250505

Website: www.mndassociation.org

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**This resource has been evidenced,
user tested and reviewed by experts.**

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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