



COMING HOME GUIDE

Caring for someone with MND: a family guide

Motor neurone disease, for England, Wales, Scotland and
Northern Ireland

Version 1.0.1 • October 2026. Next review: October 2027

About this guide

This guide is correct at October 2026, version 1.0. We've written it in good faith as general guidance to help carers and families. It isn't legal, financial or medical advice. Rules and rates change, so before you act, please make sure you have the latest version of this guide and look at the official sources: GOV.UK, Social Security Scotland, nidirect and your local council. To the extent the law allows, we can't accept liability for any errors or omissions, or for decisions made on the strength of this guide. In a medical emergency call 999. For urgent advice, contact NHS 111.

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How to use this guide

Version 1.0.1. October 2026. Next review: October 2027. Information read on 3 October 2026. We review this guide every year, and straight away if a service or rule it describes changes.

Who this guide is for: you, if you look after someone with motor neurone disease (MND). That might be your partner, your mum or dad, a brother or sister, a grown-up child or a close friend. You might live with them, live nearby, or help from far away. It covers England, Wales, Scotland and Northern Ireland.

How to use it: you don't need to read it all at once. Section 1 is about you. Sections 2 and 3 explain MND in plain words and who's in the team. Section 4 covers the things families often plan for, and section 5 covers everyday life at home. Section 6 is about talking about the future. Sections 8 and 9 cover money, rights and NHS-funded care, and section 10 is about looking after yourself. Every fact has a source and a date, and the full list is in "Sources" at the back.

Guidance, not advice. This guide describes what many families plan for, and where to get help. It can't tell you what's happening for the person you care for, what will happen next, or what care, equipment or medicines they need. Only the MND team, the specialist nurse, their GP and the health professionals who know them can do that.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

For MND support, call the MND Association's MND Connect helpline on 0808 802 6262, or MND Scotland on 0141 332 3903 if you live in Scotland (see "Who to call").

01

You're not on your own



Hearing that someone you love has MND can turn everything upside down. You might feel shocked, frightened, angry or numb. You might want to fix everything at once, or not want to think about it at all. You might feel close one day and overwhelmed the next.

All of that is common. The MND Association says the news is emotional for everyone involved, and that feelings can be unpredictable and intense. These are natural reactions ([MND Association, Emotions, thinking and behaviour, updated 21 Aug 2026](#)).

Families often say the hardest part is keeping up. Appointments, equipment, adaptations, benefits and big conversations can all arrive close together. This guide is here to help you organise, so there's a little less to hold in your head.

What this guide does: it brings together what the NHS and the MND charities say about the team around you, the things families often plan for, everyday life, money and rights, and the help you can ask for.

What it doesn't do: it doesn't say how MND will change for the person you care for, how fast, or what's right for them. The NHS says the symptoms affect everyone differently, and how quickly things change can vary from person to person ([NHS, Motor neurone disease, reviewed 19 Feb 2025](#)). The MND team or specialist nurse can talk this through with you both.

02

MND in plain words



The NHS explains that MND affects nerves in the brain and spinal cord called motor neurones, which tell the muscles what to do (NHS, Motor neurone disease). It can affect moving about, speech and communication, breathing, swallowing, eating and drinking, emotions and thinking, and relationships and family life (NHS, Motor neurone disease).

It affects everyone differently. Not everyone has every symptom (NHS, Motor neurone disease).

If you want to know more about the type of MND they have, or what to expect for them, ask the MND team or specialist nurse. They can talk this through, in as much or as little detail as you both want.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

03

The team around you



Who's who

The NHS says people with MND have support from a team of health professionals, which may include a specialist nurse, a brain and nerve specialist (neurologist), a physiotherapist and an occupational therapist. Speech and language therapists also help (NHS, Motor neurone disease). You may also meet a dietitian, a respiratory team who help with breathing, social care staff, and the GP.

Palliative care and hospice teams help with comfort and quality of life. The NHS says end of life care can be at home, in hospital, in a care home or in a hospice ([NHS, End of life care, read 3 Oct 2026](#)). Meeting these teams doesn't have to mean the end is near. Ask the specialist nurse when they can be involved.

How often you'll see them

The NHS says there should be an appointment with the care team every 2 or 3 months, to talk about any changes and needs (NHS, Motor neurone disease).

MND care centres and networks

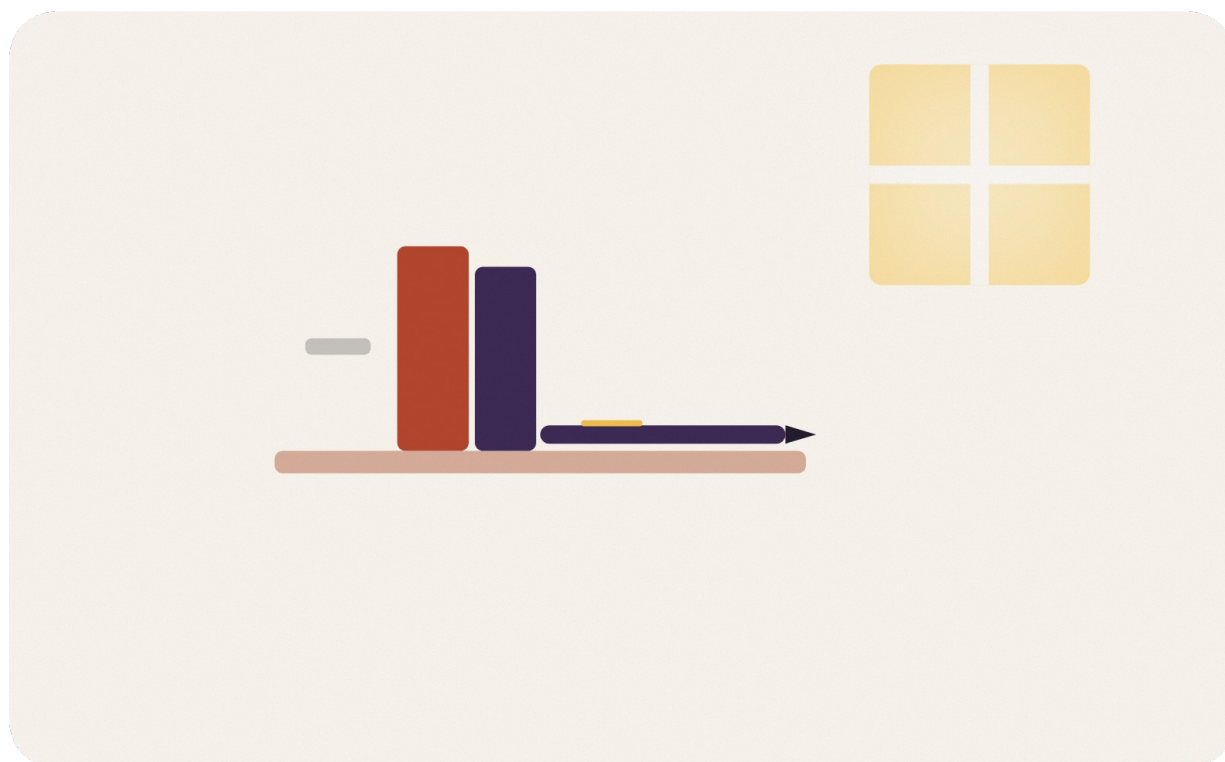
The MND Association has set up MND care centres and networks across England, Wales and Northern Ireland. They have a dedicated MND clinic, a single point of contact and a team of different professionals, and they work alongside the person's own care team. Not everyone goes to a care centre, because many hospitals provide good care too. MND Connect can tell you where support is nearest ([MND Association, Care centres and networks, read 3 Oct 2026](#)).

Out of hours, the MND Association says to contact the GP's out of hours number for health problems, or the council's adult social care emergency duty team for social care concerns (MND Association, Care centres and networks).

Keeping track

There can be a lot of people and appointments. Some families find these help:

- one notebook, or one shared place, for names, numbers and questions
- one shared calendar for appointments and visits
- one person as the main family contact for the team, if that suits you



04

Things families often plan for



MND brings decisions, often close together. This section explains, in the NHS's and the MND charities' words, what families commonly need to plan for, and who to ask. It isn't advice about what to choose or when. Each of these is a conversation for the person with MND, their family and the specialist team. The MND team or specialist nurse can talk each one through.

Moving about and wheelchairs

The occupational therapist and physiotherapist can help with moving about safely, equipment and changes at home (NHS, Motor neurone disease).

For a wheelchair, the GP or a health or social care professional can refer them to the NHS wheelchair service for an assessment. The MND Association says it's important to have this assessment as early as possible, so the service can look at their posture, how they'll use the chair and their home ([MND Association, Wheelchair support, read 3 Oct 2026](#)).

Speech and communication

MND can affect speech. The MND Association says that before buying any equipment, it's worth asking the GP for a referral to a speech and language therapist for an assessment, because many communication aids are expensive

and needs can change. The speech and language therapist can advise on ways to use the voice and on communication aids to suit them ([MND Association, Speech and communication, updated 21 Aug 2026](#)).

Voice banking and message banking. The MND Association describes two things people sometimes do:

- **Message banking:** recording words, phrases or longer messages in their own voice, to play back later.
- **Voice banking:** recording sample words and phrases to create a computer version of their voice, which can then say new things.

It says voice banking works best before any major changes to speech, and that family members can bank their voices if speech has already become hard. MND Connect can give guidance on the process ([MND Association, Speech and communication](#)). Ask the speech and language therapist if this is something to talk about.

Eating and drinking

If MND affects swallowing, the MND Association says mealtimes can take longer and people may eat less. The speech and language therapist and dietitian can help ([MND Association, Swallowing, eating and drinking, updated 21 Aug 2026](#)). Follow any advice they give about food and drink, and ask them if anything isn't clear.

The MND Association also explains that some people decide to have a feeding tube, as another way to get the food and drink they need. It says being fully informed can help people make decisions in good time ([MND Association, Swallowing, eating and drinking](#)). Whether this is right for someone is a decision for them, with the specialist team.

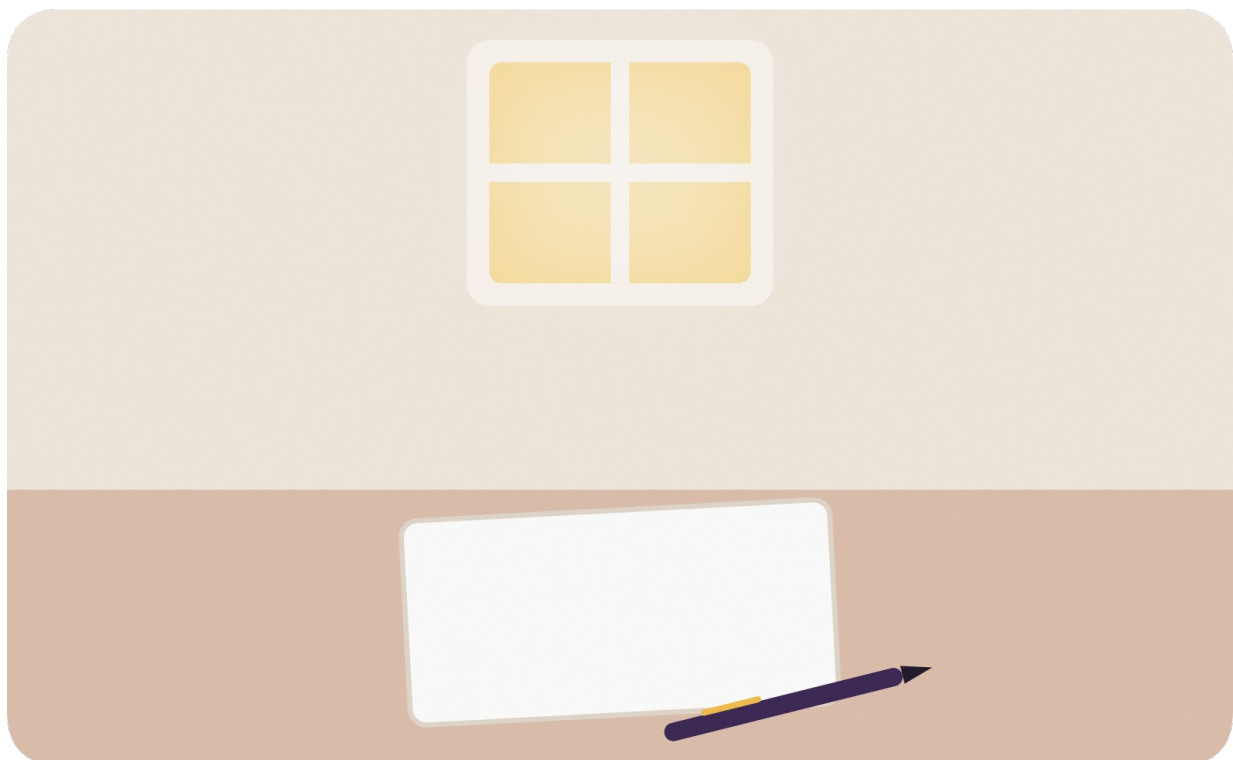
Breathing

The MND Association says MND can weaken the muscles used for breathing, which can lead to tiredness and breathlessness. A respiratory consultant can assess breathing, and talk about support. One kind of support, called non-invasive ventilation (NIV), uses a small machine and a nose or face mask to help the flow of air into the lungs. It says open conversations with the respiratory

team can help when deciding about breathing support ([MND Association, Breathing and ventilation, updated 21 Aug 2026](#)). Whether and when is for the person and the team to talk through.

Information for emergency staff

The MND Association provides ways to let health professionals know about the person's needs in an emergency, including a wristband (MND Association, Breathing and ventilation). Ask MND Connect or the specialist nurse what's available, and what emergency staff should know.



05

Day to day at home



Personal care

Help with washing, bathing and dressing may be part of their care (NHS, Motor neurone disease). It can feel awkward for both of you, especially between partners or a parent and child. Ask how they'd like things done, give them time, and let them do what they can. The occupational therapist can suggest equipment and other ways of doing things.

Energy and rest

Tiredness is common. Some families find it helps to plan the day around the times the person has the most energy, and to leave room for rest.

Feelings, thinking and behaviour

The MND Association says some people with MND have emotional lability, where they laugh or cry in ways that don't match how they feel. It doesn't affect everyone, and it can be distressing for the person and those close to them. Explaining it to others can help (MND Association, Emotions, thinking and behaviour).

It also says some people have changes in thinking and behaviour, such as how they take in information, use language or react to others. If you notice changes, ask the GP or the MND team about an assessment (MND Association, Emotions, thinking and behaviour). If they seem very low or anxious, talk to the GP.

Talking therapies can help with worry and low mood (NHS, Motor neurone disease).

Keeping life going

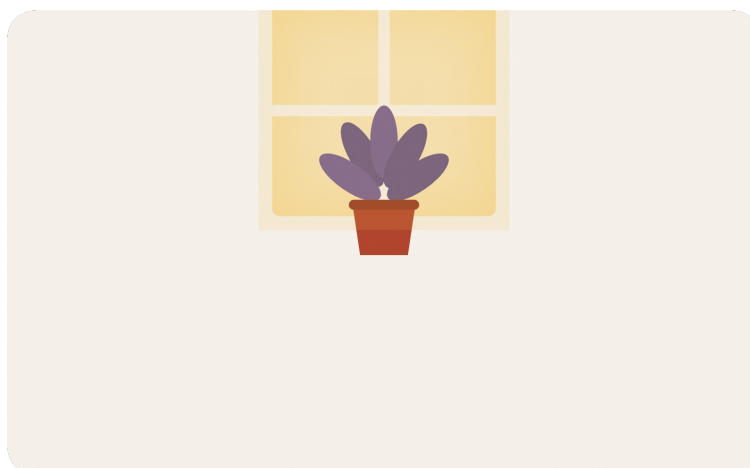
Keep doing what they enjoy, in whatever way works now: music, visits, time outside, favourite programmes, family meals. The person is still the person, and their choices matter.

Safety and adapting the home

The MND Association says equipment, home adaptations and devices to work things like lights and doors can be expensive, but there may be help through loans and grants ([MND Association, Safety at home, updated 21 Aug 2026](#)). The NHS mentions home adaptations such as handrails as part of the support people may need (NHS, Motor neurone disease).

Building work can take months, so it can help to ask early. See our guides to adapting a home ([Coming Home, Adapting a home](#)) and Disabled Facilities Grants ([Coming Home, Disabled Facilities Grants](#)).

If they go into hospital, our Hospital discharge guide explains what should happen before they come home ([Coming Home, Hospital discharge](#)).



06

Talking about the future



This section is gentle on purpose. You don't have to read it now. When you're both ready, it can help to talk while the person can say what they want, so their wishes are known.

The MND Association has information on planning ahead, including ways to open hard conversations, putting affairs in order, and recording decisions about future care ([MND Association, Planning ahead, updated 19 Aug 2026](#)).

Power of attorney

A power of attorney lets someone they trust make decisions for them if they can't. The MND Association says Northern Ireland uses an Enduring Power of Attorney, registered through the Office of Care and Protection, which covers property and money only (MND Association, Planning ahead). Our power of attorney guide explains the rules in each nation ([Coming Home, Power of attorney](#)).

Recording wishes about future care

England and Wales: an advance decision to refuse treatment (ADRT) is a decision someone makes now to refuse a specific kind of medical care in the future, if they can't make or communicate the decision themselves. Everything they're refusing must be named in it. An advance decision isn't the same as an advance statement, which sets out wishes and preferences more generally

([NHS, Advance decision \(living will\), reviewed 19 Sep 2023](#)). The MND Association says an ADRT is legally binding (MND Association, Planning ahead). The NHS suggests talking it through with a doctor or nurse who knows them before deciding (NHS, Advance decision).

Scotland: this is called future care planning. People can ask their doctor, nurse or care team about making a future care plan, which can be added to their health record and updated at any time ([NHS inform, Future care planning, read 3 Oct 2026](#)).

Northern Ireland: ask the specialist nurse, the GP or the Health and Social Care Trust how to record wishes about future care.

End of life care

When the time comes, our guide to end of life care will help ([Coming Home, End of life care](#)). The NHS end of life care pages explain what it involves, where it can happen and how to plan ahead (NHS, End of life care).

The MND team, specialist nurse or GP can talk any of this through with you both.

07

If things change suddenly



In an emergency, for example if they're struggling to breathe or choking and it isn't easing, call 999.

For other sudden changes, for example if they become much more breathless, drowsy, confused or unwell over hours or days, contact the GP or NHS 111 the same day, or the number the MND team has given you. In an emergency, call 999.

Keep the team's numbers, and any emergency information the team or MND Association has given you, by the phone where everyone can find them.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

08

Money and rights



MND can bring extra costs, and sometimes less income. You don't have to work it all out at once. Our other guides have the figures and the details.

- **For them, if they're over State Pension age:** Attendance Allowance ([Coming Home, Attendance Allowance](#)).
- **For them, if they're under State Pension age:** Personal Independence Payment, or Adult Disability Payment in Scotland ([Coming Home, PIP](#)).
- **For you:** Carer's Allowance ([Coming Home, Carer's Allowance](#)).
- **Other help with money:** Council Tax, help with bills and more ([Coming Home, Money and help](#)).
- **Getting out:** a Blue Badge can help with parking ([GOV.UK, Apply for a Blue Badge, read 3 Oct 2026](#)).

You can also use the Benefits finder to see what might apply:

www.cominghomecare.app/benefits-check?ref=guide-mnd

The special rules for end of life

Some benefits can be paid more quickly, and at a higher rate, under what GOV.UK calls the special rules for end of life. This is how GOV.UK defines who is eligible. It's a benefit rule, not a statement about the person you care for. GOV.UK says someone is eligible if both of these apply:

- they have an illness that gets worse over time
- their doctor or medical professional has said they might have 12 months or less to live

GOV.UK says that if a medical professional hasn't talked to them about this, they can still ask whether the professional will support a claim under the special rules. The doctor or medical professional fills in a form called SR1 ([GOV.UK, Get benefits if you're nearing the end of life, read 3 Oct 2026](#)). The same special rules apply to PIP in Northern Ireland ([nidirect, Personal Independence Payment, read 3 Oct 2026](#)). Our Attendance Allowance and PIP guides explain how to claim.

Scotland has different rules. Social Security Scotland says a registered doctor or nurse confirms the illness on a form called BASRiS, and that, unlike the UK system, it doesn't need someone to have a fixed life expectancy to apply under its fast-track process ([Social Security Scotland, Special Rules for Terminal Illness, read 3 Oct 2026](#)).

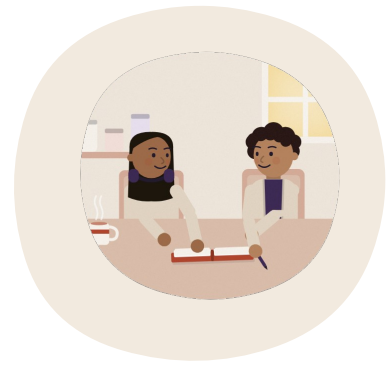
Ask the specialist nurse or GP whether they'd support a claim. It's a form, and it can be a hard conversation, but it can make a real difference to money.

Charity grants

The MND Association has Support Funds in England, Wales and Northern Ireland. They can help with household bills and food, equipment and technology someone has been assessed as needing, and the wellbeing of the person with MND and their family, including unpaid carers and children ([MND Association, Support Funds, read 3 Oct 2026](#)). In Scotland, MND Scotland offers grants and advice on benefits ([MND Scotland, Support, read 3 Oct 2026](#)).

09

NHS continuing healthcare



NHS continuing healthcare is care arranged and funded by the NHS for some adults with long-term complex health needs ([NHS, NHS continuing healthcare, reviewed 11 Apr 2024](#)).

The fast-track pathway (England). The NHS says someone who is nearing the end of their life, and whose health is changing quickly, should be considered for the NHS continuing healthcare fast-track pathway, so that care and support can be put in place as soon as possible, usually within 48 hours (NHS, NHS continuing healthcare). The form professionals use is called the Fast Track Pathway Tool ([GOV.UK, NHS continuing healthcare fast track pathway tool, read 3 Oct 2026](#)).

Wales: this is called Continuing NHS Healthcare. The Welsh Government says that if someone's condition is changing quickly and their need for care is increasing, possibly because they may be nearing the end of their life, staff should ask for a fast track assessment, which should be completed within 2 working days ([Welsh Government, Continuing NHS Healthcare: how it is organised if you are eligible, updated 21 Sep 2026](#)).

Scotland: NHS continuing healthcare was replaced in 2015 by Hospital Based Complex Clinical Care, which is hospital based care for people whose care needs can only be met in hospital ([Care Information Scotland, read 3 Oct 2026](#)). Ask the specialist nurse or GP what applies.

Northern Ireland: ask the specialist nurse, the GP or the Health and Social Care Trust about help with complex care needs.

If you think this might apply, ask the specialist nurse or GP.

10

Looking after yourself



Caring for someone with MND can take everything you have. Looking after yourself isn't selfish. It helps you keep going, and it helps them too.

Your feelings. You might feel grief long before any loss, for the life you'd planned, the conversations, the things you did together. The MND Association says feelings can be unpredictable and intense, and that these are natural reactions (MND Association, Emotions, thinking and behaviour). Many carers say talking to someone who understands helps.

Your rights. The MND Association says you have the right to ask for a carer's assessment, whether or not you live with the person, and whether you care full time, part time, or alongside paid work. It also suggests registering as a carer with your GP ([MND Association, Support for carers, updated 9 Sep 2026](#)).

Small things that help:

- Ask the council for a carer's assessment (the Health and Social Care Trust in Northern Ireland), or for an Adult Carer Support Plan in Scotland ([mygov.scot, Help if you're a carer, updated 12 Sep 2025](#)).
- Tell your GP you're a carer.
- Take breaks, even short ones. Ask the council about breaks for carers.
- Talk to MND Connect, MND Scotland or Carers UK. MND Scotland has a counselling service for carers (MND Scotland, Support).

- If there are children in the family, the MND Association and MND Scotland both have support for children and young people.
- Let people know what they could do to help, even small things.

If you're worried about your own health, contact your GP or NHS 111. In an emergency call 999.



11

Across the four nations



England: the NHS MND pages, MND Association care centres and networks, your council's adult social services, and MND Connect.

Wales: NHS 111 Wales has an MND page ([NHS 111 Wales, Motor neurone disease, read 3 Oct 2026](#)). The MND Association covers Wales, including the South Wales Care Network (MND Association, Care centres and networks) and an All Wales virtual support group ([MND Association, Online support groups, read 3 Oct 2026](#)).

Scotland: MND Scotland supports people with MND and their families. Its National Support Advisers can help with benefits, housing, adaptations and social care, and it has counselling, grants, and support with communication and technology ([MND Scotland, Support](#)). MND Connect is for England, Wales and Northern Ireland, and suggests people in Scotland contact MND Scotland ([MND Association, MND Connect, read 3 Oct 2026](#)). NHS inform has MND information ([NHS inform, Motor neurone disease, read 3 Oct 2026](#)).

Northern Ireland: the Northern Ireland MND Care Network is based at the Royal Victoria Hospital in Belfast, with an MND nursing helpline ([MND Association, Northern Ireland Care Network, read 3 Oct 2026](#)). The Northern Ireland branch of the MND Association is run by volunteers. It has trained Association Visitors, informal support meetings, and can help with specialist equipment and access to small grants ([Motor Neurone Disease Association Northern Ireland, read 3 Oct 2026](#)). The Health and Social Care Trust does the needs assessment and the carer's assessment ([nidirect, Assessments for carers, read 3 Oct 2026](#)). nidirect has MND information ([nidirect, Motor neurone disease, read 3 Oct 2026](#)).

12

How Coming Home can help



Coming Home: Family Care is an iPhone app for families looking after someone. It's coming soon. It helps you organise. It isn't medical advice, and it can't tell you what's happening for the person you care for.

The care circle brings the family, friends and neighbours who help into one place, with shared notes, tasks and a calendar. Use it to keep track of the many appointments and visits, and who's doing what.

Everyone in the circle can join at no cost.

The family care diary helps you note changes and questions as they come up, so you have dates and examples ready for the MND team, the GP, or a benefit form.

Every plan includes the 8 quick questions on what you might be entitled to, and a lasting power of attorney to-do list.

Care Plus (£14.99 a month or £99.99 a year) includes a 20 GB document vault, stored in the UK, for the care plan, the power of attorney, and documents about their wishes for future care.

To hear when Coming Home is ready, join the waitlist:

www.cominghomecare.app/?ref=guide-mnd

Built by people who know home care.

13

Who to call



This guide is guidance, not advice. For support and advice:

- **MND Association MND Connect helpline** (England, Wales and Northern Ireland): 0808 802 6262, Monday to Friday 9am to 4pm. Interpreters are available (MND Association, MND Connect)
- **MND Scotland:** 0141 332 3903, Monday to Friday 9am to 5pm (MND Scotland, Support)
- **Northern Ireland MND Care Network nursing helpline:** 028 9504 2235, Monday to Friday 9am to 1pm, not bank holidays (MND Association, Northern Ireland Care Network)
- **Carers UK Helpline:** 0808 808 7777, Monday to Friday 9am to 6pm ([Carers UK, Helpline and other support, read 3 Oct 2026](#))
- **Age UK Advice Line:** 0800 678 1602, 8am to 7pm, every day of the year ([Age UK Advice Line, read 3 Oct 2026](#))
- **Advice NI:** 0800 915 4604 ([Advice NI, Contact, read 3 Oct 2026](#))
- **Samaritans**, if you need to talk to someone straight away: 116 123 (MND Association, MND Connect)
- **Your council's adult social services** (the Health and Social Care Trust in Northern Ireland) for a needs assessment and a carer's assessment
- **The MND team or specialist nurse**, on the number they've given you

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

14

Sources

All read on 3 October 2026 unless another date is given. Dates in brackets are the page's own published, updated or reviewed date.

NHS

- NHS, Motor neurone disease (reviewed 19 Feb 2025): www.nhs.uk/conditions/motor-neurone-disease/
- NHS, End of life care: www.nhs.uk/tests-and-treatments/end-of-life-care/
- NHS, Advance decision (living will) (reviewed 19 Sep 2023): www.nhs.uk/tests-and-treatments/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/
- NHS, NHS continuing healthcare (reviewed 11 Apr 2024): www.nhs.uk/social-care-and-support/money-work-and-benefits/nhs-continuing-healthcare/
- NHS inform, Motor neurone disease: www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/motor-neurone-disease-mnd/
- NHS inform, Future care planning: www.nhsinform.scot/care-support-and-rights/decisions-about-care/future-care-planning/
- NHS 111 Wales, Motor neurone disease: 111.wales.nhs.uk/motorneuronedisease/
- nidirect, Motor neurone disease: www.nidirect.gov.uk/conditions/motor-neurone-disease

Official

- GOV.UK, Get benefits if you're nearing the end of life: www.gov.uk/benefits-end-of-life
- nidirect, Personal Independence Payment: www.nidirect.gov.uk/articles/personal-independence-payment-pip
- Social Security Scotland, Special Rules for Terminal Illness: www.socialsecurity.gov.scot/special-rules-for-terminal-illness
- GOV.UK, NHS continuing healthcare fast track pathway tool: www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool

- Welsh Government, Continuing NHS Healthcare: how it is organised if you are eligible (updated 21 Sep 2026):
www.gov.wales/continuing-nhs-healthcare-how-it-organised-if-you-are-eligible-html
- Care Information Scotland, Hospital based care for complex needs:
www.careinfoscotland.scot/topics/how-to-get-social-care-support/hospital-based-complex-clinical-care/
- GOV.UK, Apply for a Blue Badge: www.gov.uk/apply-blue-badge
- mygov.scot, Help if you're a carer (updated 12 Sep 2025):
www.mygov.scot/help-for-carer
- nidirect, Assessments for carers: www.nidirect.gov.uk/articles/assessments-carers

Charities

- MND Association, MND Connect:
www.mndassociation.org/support-and-information/our-services/mnd-connect
- MND Association, Care centres and networks: www.mndassociation.org/support-and-information/our-services/care-centres-and-networks
- MND Association, Northern Ireland Care Network: www.mndassociation.org/support-and-information/our-services/care-centres-and-networks/northern-ireland
- MND Association, Online support groups:
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- MND Association, Wheelchair support:
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- MND Association, Speech and communication (updated 21 Aug 2026):
www.mndassociation.org/support-and-information/living-with-mnd/speech-and-communication
- MND Association, Swallowing, eating and drinking (updated 21 Aug 2026):
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- MND Association, Breathing and ventilation (updated 21 Aug 2026):
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- MND Association, Emotions, thinking and behaviour (updated 21 Aug 2026):
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- MND Association, Support Funds: www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd

- MND Scotland, Support: mndscotland.org.uk/support/
- Motor Neurone Disease Association Northern Ireland: mndnorthernireland.org/
- Carers UK, Helpline and other support:
www.carersuk.org/help-and-advice/helpline-and-other-support/
- Age UK Advice Line: www.ageuk.org.uk/services/age-uk-advice-line/
- Advice NI, Contact: www.adviceni.net/contact

15

Changelog

Version	Date	What changed	Why
1.0	October 2026	First published	Information read on 3 October 2026

1.0.1. October 2026. Corrected the line about who builds Coming Home (section 12). Accuracy. No change to the advice.

The next review is due in October 2027, or straight away if a service or rule changes. The latest version is always at www.cominghomecare.app/guides/mnd



Coming Home

Less to hold in your head.

www.cominghomecare.app

Find the latest version at cominghomecare.app/guides/mnd

This edition

Version	1.0
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Next review	October 2027



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