

CONDITION GUIDE

Motor neurone disease (MND): a plain-English guide

For people living with MND and the families beside them. Clear information, the questions people ask, what helps day to day, and how the NDIS, aged care and Kinship fit together.

Motor neurone disease (MND) is the name for a group of diseases that affect motor neurones, the nerve cells that carry messages from the brain to the muscles. Those messages let us walk, talk, swallow and breathe. In MND, the motor neurones are damaged and die, and the muscles gradually weaken (MND Australia; healthdirect).

Early signs vary. Some people notice stumbling, trouble gripping, or slurred speech and swallowing changes. How fast MND progresses is different for each person. There's no cure, and MND is life-limiting. MND Australia's message is that coordinated care from a team of health professionals helps people live better for longer.

MND doesn't affect sight, hearing, smell, taste or touch (healthdirect). Most of the time the cause isn't known.

A note on words: we follow MND Australia and talk about "people living with MND". Its motto is worth borrowing: until there's a cure, there's care.

Key facts

- **Almost 2,800** Australians were living with MND in 2025
- **2 a day** Australians are diagnosed with MND
- **About half** of people with MND are diagnosed under 60
- **1 in 300** lifetime risk of MND by age 85

Figures: AIHW, Motor neurone disease in Australia (2,800); MND Australia (diagnoses, age and lifetime risk).



What helps, day to day

- **Talk to your MND Association early.** The MND Info Line, 1800 777 175, puts you through to your local MND Association. Calls are free and confidential.
- **A specialist MND clinic.** MND clinics in most capital cities and major centres bring the health professionals together in one place (MND Australia).
- **Plan ahead, on your terms.** Planning ahead, even early, can offer a sense of control and make sure your care wishes are known (MND Australia).
- **Equipment as things change.** Mobility aids, communication devices and other equipment may be recommended (healthdirect). MND Associations can rent equipment, and the NDIS can fund it (MND Australia).
- **Support for the people who care.** Carer Gateway: 1800 422 737. For emotional support after a diagnosis, healthdirect points to Medicare Mental Health: 1800 595 212.

How the NDIS can help

To be eligible for the NDIS you need to be younger than 65 when your application is received, an Australian citizen or permanent resident (or Protected Special Category visa holder) living in Australia, and have an impairment that's likely to be permanent and substantially reduces your ability to do everyday things.

For MND, the timing matters. The NDIS has a priority pathway for people with MND. If you become a participant before you turn 65, you can stay on the NDIS after 65, unless you later move into aged care or start aged care support at home (NDIS; MND Australia). If you're already 65 or older, contact My Aged Care on 1800 200 422.

- 1 Connect with an NDIS partner (use the office finder at [ndis.gov.au](https://www.ndis.gov.au)) or call the NDIS on 1800 800 110.
- 2 Work with your treating health professional to gather evidence about your disability and how it affects daily life.
- 3 Complete your application with your NDIS partner, or by yourself using the access request form.
- 4 Submit it. Your NDIS partner can do this for you, or use the NDIS service hub, post it (NDIA, GPO Box 700, Canberra ACT 2601) or take it to a local office.
- 5 Wait for the decision. The NDIS tells you within 90 days once your application and all your evidence are in. You can ask for a review if you disagree.

The NDIS is changing. New NDIS laws passed in August 2026. From 1 October 2026, budgets for social and community participation and for daily living skills are being reduced as plans are reassessed or newly approved, and a new way of planning is due from April 2027. Check [ndis.gov.au](https://www.ndis.gov.au) for the latest.



How Kinship Uniting Services can help

We support people, not diagnoses. For someone living with MND, here's where we can help.

- **Personal care and daily living.** Showering, dressing, meals and the house, done the way you want them done.
- **PEG feeding and medication.** PEG feeding, medication management and complex bowel care are on our registered high intensity list.
- **Community participation.** Keeping up the things you love, for as long as you want to.
- **Aged care is a different system.** Our CHSP-funded aged care is domestic assistance only, in Northern Sydney and the Southern Highlands. We're applying to deliver Support at Home but can't take clients under it yet.
- **Private nursing and help at home.** Anyone can book privately while funding is sorted, or alongside it. Private nursing is from \$120 an hour plus GST. Other services: call for a quote.
- **The same face every visit.** The same support worker comes every visit, so nobody has to explain themselves to a stranger each week. Families get updates as standard.

Continence support. If getting to the bathroom becomes harder as mobility changes, continence products can be part of staying comfortable at home. For independent advice, call the National Continence Helpline (1800 33 00 66). Equipit sells continence products such as adult nappies and continence briefs. Equipit is the product-supply arm of Kinship Uniting Services, an NDIS registered and CHSP approved provider since 2017. Order online at equipitdsp.com. Disclosure: Equipit is part of the same family of businesses as Kinship, and Equipit itself is not NDIS registered. You're free to buy from any supplier. Agency-managed NDIS funds can't be spent with Equipit; if you're self-managed or plan-managed, check with your plan manager first.

Where to get help

- **MND Info Line:** 1800 777 175 (connects to your state MND Association)
- **NDIS (under 65):** 1800 800 110, and say you have MND
- **My Aged Care (65 and over):** 1800 200 422
- **Medicare Mental Health:** 1800 595 212
- **Carer Gateway:** 1800 422 737
- **National Continence Helpline:** 1800 33 00 66
- **Kinship Uniting Services:** 0437 733 744 or 0424 756 143, info@kinshipunitingservices.com, 39 Victory Road, Colebee NSW 2761

Your checklist

- ☐ Call the MND Info Line (1800 777 175) and ask about your local MND Advisor
- ☐ Ask your neurologist about a referral to an MND clinic
- ☐ Under 65? Call the NDIS (1800 800 110) and tell them you have MND
- ☐ 65 or over? Register with My Aged Care (1800 200 422) and ask about the priority pathway
- ☐ Write down your care wishes and who should know them
- ☐ List the equipment you use now and what may be needed next
- ☐ Ask your support team to note changes, so your plan can keep up

Questions people ask

How long do people live with MND?

It varies a lot. MND Australia gives an average life expectancy of 2 to 3 years from diagnosis, and healthdirect notes some people live a long time. Your neurologist is the best person to talk to about your own situation.

Is MND genetic?

Usually not. healthdirect says around 1 in 10 cases are inherited (familial MND), and MND Australia puts it at up to 15%. If MND runs in your family, a genetic counsellor can talk through testing.

What are the first symptoms of MND?

Often mild: stumbling from weak leg muscles, trouble holding objects, slurred speech or swallowing changes, cramps and twitching. They usually start on one side and spread (healthdirect).

Is MND the same as ALS?

ALS (amyotrophic lateral sclerosis) is one type of MND. The group also includes progressive muscular atrophy, progressive bulbar palsy, primary lateral sclerosis and Kennedy's disease (healthdirect).

Is MND painful?

It can be. healthdirect lists cramps, pain and discomfort among the symptoms. Your MND clinic, GP and palliative care team can help manage them.

Can you get the NDIS for MND?

Yes, if you apply before 65. The NDIS has a priority pathway for people with MND, and MND Australia says to call the NDIS on 1800 800 110 and tell them you have MND. If you're 65 or older, older Australians with MND get priority access to Support at Home through My Aged Care (NDIS).

Talk to a real person. Call Kinship Uniting Services on **0437 733 744** or email info@kinshipunitingservices.com. Deaf, or have a hearing or speech impairment? Contact us through the National Relay Service: Speak & Listen 1300 555 727, TTY 133 677, SMS relay 0423 677 767.



Sources

MND Australia: What is motor neurone disease? —

<https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd>

MND Australia: Newly diagnosed — <https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/newly-diagnosed>

MND Australia: Government support and benefits (NDIS and My Aged Care) —

<https://www.mndaustralia.org.au/info/find-services-support/government-support-and-benefits/>

healthdirect: Motor neurone disease (MND) — <https://www.healthdirect.gov.au/motor-neurone-disease>

AIHW: Motor neurone disease in Australia — <https://www.aihw.gov.au/reports/neurological-conditions/mnd>

NDIS: How to check your eligibility — <https://www.ndis.gov.au/applying/eligibility-requirements/how-check-your-eligibility>

NDIS: What are the NDIS disability requirements —

<https://www.ndis.gov.au/applying/eligibility-requirements/what-are-ndis-disability-requirements>

NDIS: How to apply — <https://www.ndis.gov.au/applying/application-process/how-apply>

NDIS: Securing the NDIS for future generations (new NDIS laws) —

<https://www.ndis.gov.au/ndis-laws/securing-ndis-future-generations>

NDIS: New way of planning — <https://www.ndis.gov.au/changes-ndis/new-way-planning>

My Aged Care (phone 1800 200 422) — <https://www.myagedcare.gov.au/>

Continence Health Australia: National Continence Helpline —

<https://www.continence.org.au/help-and-support/national-continence-helpline/>

Medicare Mental Health (national phone service 1800 595 212) — <https://www.medicarementalhealth.gov.au/>

Carer Gateway — <https://www.carergateway.gov.au/>

NDIS: Priority aged care support for Australians with MND (4 June 2026) —

<https://www.ndis.gov.au/news/11558-priority-aged-care-support-australians-mnd>

NDIS: Guide to residential aged care (staying on the NDIS after 65) —

<https://www.ndis.gov.au/participants/life-transitions/transitioning-other-systems/guide-residential-aged-care>

NDIS: Guide to leaving the NDIS — <https://www.ndis.gov.au/participants/life-transitions/leaving-ndis/guide-leaving-ndis>