

CONDITION GUIDE

Living well with multiple sclerosis

A plain-English guide for people living with MS, their families and carers in Australia

Some days you can do everything. Some days the shower takes it all. MS looks different for everyone, and it can look different for the same person from one week to the next. This guide brings together practical ideas from MS Australia and MS Plus, the NDIS and aged care pathways, and the questions worth asking along the way.

It is general information only. Your neurologist, MS nurse or GP knows your situation and should guide your care.

MS in plain English

Multiple sclerosis (MS) is a condition of the central nervous system: the brain, spinal cord and optic nerves. The immune system attacks myelin, the protective coating around nerves, so messages slow down or don't get through. MS Australia says there is no single known cause; genetic and environmental factors both play a part.

MS Australia estimates **37,756 Australians** were living with MS in 2025. MS Australia's key facts (checked October 2026) say around three in four people diagnosed are women, the average age at diagnosis is 20 to 40, and about 85% are first diagnosed with relapsing remitting MS, where symptoms flare and then settle. There is no cure yet, but MS Australia says 15 disease-modifying therapies are available in Australia. MS Plus notes that MS is lifelong but not terminal, and not everyone with MS develops a disability.

- **Common symptoms:** fatigue, tingling or numbness, weakness or stiffness, balance and walking changes, blurred or double vision, memory and concentration changes, mood changes, heat sensitivity, and bladder or bowel changes.
- **Invisible symptoms:** many people look well while dealing with exhaustion, pain or thinking changes. MS Australia stresses that how someone looks doesn't show what they're experiencing.

Everyday tips that help

These ideas come from MS Australia and MS Plus. Try what suits you and leave the rest.

- **Pace your energy.** MS fatigue isn't ordinary tiredness; MS Australia, citing the US National Multiple Sclerosis Society, says around 80% of people with MS experience it at some point. Alternate demanding and lighter tasks, plan rests, and save energy for what matters most. An occupational therapist or physio can tailor a plan.
- **Keep cool.** Heat can temporarily worsen symptoms. Try cold drinks, shade and a hat, loose clothing, fans or air-conditioning, and a cool shower before activity.
- **Make home tasks easier.** Sit for jobs where you can, keep everyday items within reach, and ask about equipment that saves energy.
- **Move in a way that suits you.** MS Australia lists exercise, sleep, good food and enough water among the ways to manage fatigue.
- **Know what a relapse looks like.** MS Plus describes it as new or worsening symptoms lasting at least 24 hours, with no other explanation such as infection, stress or heat. Tell your neurologist, MS nurse or GP as soon as you can.

Tip: keep a simple symptom diary for a fortnight (energy, heat, sleep, bladder). It makes appointments and NDIS evidence much easier.

Bladder and bowel changes

MS can disrupt nerve messages to the bladder and bowel. MS Australia lists urgency, frequency, leaking, waking at night to pass urine, constipation and bowel accidents. These are common and treatable, and nobody needs to manage them alone.

MS Australia suggests drinking enough water, limiting caffeine and evening fluids, eating high-fibre food, and planning easy toilet access (the National Public Toilet Map at toiletmap.gov.au helps). A continence nurse can assess you and recommend products.

Kinship's sister business, Equipit, supplies continence products such as adult nappies, continence briefs and bed protection (equipitdsp.com). Equipit is the product-supply arm of Kinship Uniting Services, an NDIS registered and CHSP approved provider since 2017. Equipit is part of the same family of businesses and you are free to buy from any supplier. Equipit is not NDIS registered, so agency-managed NDIS funds can't be spent there; self-managed and plan-managed participants should check with their plan manager first.

The NDIS and aged care pathways

Under 65: you can apply to the NDIS if you are younger than 65 on the day you apply, live in Australia as a citizen, permanent resident or Protected Special Category visa holder, and meet the disability or early intervention requirements. The NDIS says it understands the impact of a disability can go up and down and come in episodes. MS Plus notes that a diagnosis alone does not guarantee access, so record how fatigue, thinking, heat and continence changes affect daily life.

Already on the NDIS when you turn 65: you can choose to stay on the NDIS or move to aged care, but you can't use both at once.

65 or older and not on the NDIS: help at home comes through aged care. Contact My Aged Care on 1800 200 422 or at myagedcare.gov.au.

Continence products: the NDIS may fund continence supports that relate to your disability, usually with evidence from a continence nurse or health professional. The Continence Aids Payment Scheme may help some people with permanent and severe incontinence.

The NDIS is changing through 2026 and 2027. Always check the latest at ndis.gov.au or call the NDIS on 1800 800 110.

Questions to ask your GP, neurologist or MS nurse

- Which type of MS do I have, and what does that mean for me?
- What treatment options suit me, and what are the side effects?
- What should I do if I think I'm having a relapse?
- Can you refer me to a continence nurse, physio or occupational therapist?
- Can you write a report about how MS affects my daily life, for an NDIS application?

Questions to ask your NDIS planner or partner

- How will my plan allow for good weeks and bad weeks?
- Can my plan include help with personal care, meals and household jobs?
- Can continence supports be included, and what evidence do you need?
- Can I keep the same support workers if my plan changes?
- What happens to my plan when I turn 65?



How Kinship Uniting Services can help

From Colebee and Blacktown to Rouse Hill and Windsor. Support that flexes with your energy, from the same support worker every visit.

We understand. With MS, what you managed on Monday might not be possible on Thursday. Fatigue, heat, bladder urgency or numb hands can turn an ordinary morning into a careful plan. It's tiring to keep explaining that to new people.

Many people with MS keep working, parenting and seeing friends, and want to save their energy for those things. Good support takes the draining jobs off your plate and leaves the rest to you.

We're qualified. Kinship Uniting Services is a registered NDIS provider (4-GWVHCEY), operating in disability and aged care since 2017, and we've supported hundreds of clients and families. Our founder, Shazia Begum, has spent more than 15 years alongside people living with disability. Our registered high intensity supports include complex bowel care, catheter care and medication management. We're registered to deliver Supported Independent Living (SIL). The same support worker comes every visit, and families get updates as standard.

Here's how we can help.

- **Daily living and personal care.** Showering, dressing, meals and the jobs that drain your energy, done with you, at your pace. Daily living support
- **Complex bowel and catheter care.** Complex bowel care, catheter care and medication management are on our registered high intensity list. High intensity support
- **Getting out and about.** Community participation, so the shops, the gym or a class you love stays part of your week. Community participation
- **Respite for the family.** A familiar support worker spends time with you at home or out in the community, so your partner or family can rest, get to their own appointments or simply have the afternoon. NDIS-funded or booked privately. Respite care
- **Supported Independent Living.** If you need support at home around the clock, we're registered to deliver SIL. Call us to talk about current availability. Supported Independent Living
- **Private nursing.** Booked privately while funding is sorted, or alongside it. Send us an enquiry and we'll talk through private nursing. Private nursing
- **Continence products.** See the continence section earlier in this guide for Equipit, our sister business, and the disclosure that goes with it.



For families, carers and referrers

For families and carers. Partners and family often pick up the slack on the hard days. We send updates as standard, so you're not left guessing, and respite with a familiar worker gives you time of your own.

For support coordinators and plan managers. If you coordinate supports or manage plans for someone with MS, tell us how their needs change between good and bad weeks, and we'll talk through a roster that fits the plan. More at kinshipunitingservices.com/for-referrers.

Where to get help

- **MS Plus Connect** (NSW, ACT, VIC, TAS): 1800 042 138, msplus.org.au
- **MS Australia national helpline:** 1300 010 158, msaustralia.org.au
- **National Continence Helpline** (continence nurse specialists): 1800 33 00 66, continence.org.au
- **NDIS:** 1800 800 110, ndis.gov.au
- **My Aged Care** (65 and over): 1800 200 422, myagedcare.gov.au
- **Carer Gateway:** 1800 422 737, carergateway.gov.au
- **healthdirect** (24/7 health advice): 1800 022 222. In an emergency, call 000.

Your checklist

- ☐ Book a GP or MS nurse appointment to talk about anything new
- ☐ Start a two-week symptom diary (energy, heat, sleep, bladder and bowel)
- ☐ Ask for a continence assessment if you have bladder or bowel changes
- ☐ Call MS Plus Connect (1800 042 138) for MS-specific advice
- ☐ Under 65? Gather reports and talk to your local NDIS partner
- ☐ 65 or older? Call My Aged Care on 1800 200 422
- ☐ Plan for summer: fan, cool drinks, shade, cooler times for errands
- ☐ Tell family or carers about the Carer Gateway (1800 422 737)



Ready to talk? We're here

If you'd like us to help with this, call 0437 733 744 and we'll talk it through. Start with what a hard day looks like. We'll tell you plainly whether and how we can help.

Call 0437 733 744 or 0424 756 143 · info@kinshipunitingservices.com · 39 Victory Road, Colebee NSW 2761 · kinshipunitingservices.com/get-support

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

MS Australia: What is MS?: <https://www.msaustralia.org.au/what-is-multiple-sclerosis-ms/>

MS Australia: MS prevalence (2025): <https://www.msaustralia.org.au/msprevalence/>

MS Australia: Types of MS: <https://www.msaustralia.org.au/types-of-ms/>

MS Australia: Key facts and figures: <https://www.msaustralia.org.au/publication/key-facts-and-figures-about-ms/>

MS Australia: Fatigue: <https://www.msaustralia.org.au/symptom/fatigue/>

MS Australia: Heat sensitivity: <https://www.msaustralia.org.au/symptom/heat-sensitivity/>

MS Australia: Bladder and bowel issues: <https://www.msaustralia.org.au/bladder-and-bowel-issues/>

MS Australia: Support services: <https://www.msaustralia.org.au/support-services>

MS Plus: Newly diagnosed: <https://www.msplus.org.au/your-neuro-condition/newly-diagnosed>

MS Plus: Managing an MS relapse:

<https://www.msplus.org.au/your-neuro-condition/what-is-ms/treating-ms/managing-an-ms-relapse>

MS Plus: Quick tips for your NDIS application:

<https://www.msplus.org.au/resources/quick-tips-to-support-your-ndis-application>

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

NDIS: Disability requirements:

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

NDIS Our Guidelines: Continence supports: <https://www.ndis.gov.au/media/7806/download>

National Continence Helpline: <https://www.continence.org.au/get-help/national-continence-helpline>

Carer Gateway: Contact us: <https://www.carergateway.gov.au/contact-us>