

I have MND. Now what?

A quick reference list with online links to information, services and resources



MND Info Line
Freecall 1800 777 175
www.mndnsw.org.au

For people living with motor neurone disease

“I had a lot of difficulty in finding information. I also didn’t know what I didn’t know. Information is found in many locations and this document brings it together to make it easier for people to find the information they are looking for.”

Paul Watson
Diagnosed with MND

“We needed a practical, person-centred and online quick reference list for people with motor neurone disease. We need to optimise early intervention, better access to services, future life planning and a multidisciplinary approach.”

Anna Fulford | Physiotherapist
Palliative Care Allied Health Team, Port Kembla Hospital
Illawarra Shoalhaven Local Health District

Visit mndnsw.org.au to view this document and links online

Contents

1. MND NSW	2
2. Government Services and Funding	3
3. Multidisciplinary Care	3
4. Assistive Technology/Equipment	5
5. Home Modifications	7
6. Planning for Now and the Future	8
7. Financial and Superannuation Advice and Assistance	8
8. Travel, Transport and Leisure	9
9. Symptom Management	10

Area of Specialist Support and Links

1. MND NSW

[MND NSW](#) provides services for people who have been diagnosed with MND in NSW, ACT and the NT including:

- 1.1. [MND Info Line](#) - information and support service for people with MND, their families and health and community care professionals ph. 1800 777 175
- 1.2. [MND Services and Resources Directory](#) is an online searchable directory of relevant services and resources.
- 1.3. [MND Advisor](#) - assists people with motor neurone disease to connect to the services they need. MND Advisors also offer ongoing information to families and service providers as questions arise or needs change. They can advise about how you can access [Government support for you](#) including [NDIS](#) for people aged under 65 and [My Aged Care](#) for people 65 years and over.
- 1.4. [Information and Education Sessions about MND](#) for people living with MND, their family and carers.
- 1.5. [Coordination of Support](#) for NDIS participants. Our Support Coordination team can assist you with the implementation of your NDIS plan.
- 1.6. [Equipment and Assistive Technology](#) through FlexEquip, the MND NSW Equipment Service. Available for all participants to access.
- 1.7. [Support Groups and Coffee Mornings](#)
- 1.8. [Newsletters](#), [online](#) information and publications.

Area of Specialist Support and Links

2. Government Services and Funding

You may be eligible for financial assistance from government programs if you have motor neurone disease

- 2.1. **Aged under 65 years** - the [National Disability Insurance Scheme \(NDIS\)](#) is a Government program for people aged under 65 years seeking information, advice and access to services. The NDIS provides community linking and individualised support, including funding, for people with permanent and significant disability. If you have NDIS funding while under 65, you can continue with NDIS funding over age 65 in most circumstances. Before contacting the NDIS, read MND NSW Guide: [NDIS - What's it all about](#)
- 2.2. **Aged 65 years and over** - [My Aged Care](#) is the Government gateway to all aged care services. Information about services and some funding for domestic assistance, personal care, meal services and nursing care. The funding program or package through which you access aged care services at home will determine how much you will need to pay.

3. Multidisciplinary Care

Multidisciplinary Care is provided by medical and allied health professionals from a variety of disciplines, who work together to address as many of a person's health and other needs as possible. Allied health professionals are health professionals who are not doctors, dentists or nurses. Allied health professionals include dietitians, occupational therapists, physiotherapists, psychologists, social workers and speech pathologists

- 3.1. You may have a multidisciplinary team at your [multidisciplinary MND Clinic](#) and/or in your [Local Health District](#)
- 3.2. To find individual medical and allied health professionals
 - 3.2.1. if you are a NDIS participant see your [NDIS Personal Portal](#) and search under 'provider locator' to find your providers by profession or budget
 - 3.2.2. if you are aged 65 years and over see [My Aged Care](#)
 - 3.2.3. ask your general practitioner, MND Advisor, Support Coordinator or search using the link by discipline below.
- 3.3. The [Dietitian](#) provides
 - advice that helps to ensure you are eating and drinking enough to maintain weight, energy levels and enjoyment of food
 - advice about symptoms that may affect eating and drinking
 - guidance on nutritional supplements and tube feeding
 - *also see below 9.7 Nutritional Needs*
- 3.4. The [Occupational Therapist](#) provides advice about
 - function and independence including mobility and driving, and using a phone, computer device or tablet
 - assistive technology/equipment and home modifications
 - reducing risk of skin pressure areas

Area of Specialist Support and Links

- *also see 9.6 Mobility, Movement and Joints, 9.7 Nutritional Needs, 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.10 Speech and Communication Needs, 9.8 Pain Management, 9.5 Insomnia, 9.1 Bladder and Bowel Management, 9.3 Cognition*
- 3.5. The [Physiotherapist](#) provides advice about
- maintaining physical activity and mobility
 - assistive technology/equipment, orthoses
 - respiratory management
 - fatigue and pain management
 - positioning for comfort
 - *also see below 9.6 Mobility, Movement and Joints, 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.8 Pain Management, 9.5 Insomnia, 9.1 Bladder and Bowel Management*
- 3.6. The [Psychologist](#)
- assesses, diagnoses and treats mental health problems
 - provides general and specific counselling
 - *also see below 9.9 Psychological and Social Care: including management of anxiety and depression, 9.5 Insomnia*
- 3.7. The [Social Worker](#)
- provides counselling on the psychological and emotional aspects of living with MND
 - assists with planning for the future
 - provides information on services and resources
 - may assist with referrals for ACAT assessments, community services and psychosocial assessments for people and carers
 - *also see below 9.9 Psychological and Social Care: including management of anxiety and depression, 9.5 Insomnia*
- 3.8. The [Speech Pathologist](#) provides advice about
- communication, including communication devices
 - swallowing, eating and drinking
 - saliva management
 - *also see below 9.7 Nutritional Needs, 9.11 Swallowing, 9.10 Speech and Communication Needs*
- 3.9. The [General Practitioner](#) (GP)
- provides routine health care such as physical examinations and immunisations
 - assesses and treats many different conditions, including illnesses and injuries
 - provides medication advice and scripts
 - makes referrals to specialists and allied health professionals
 - liaises with the neurologist and other health and community care providers
 - reports back to a specialist where an ongoing concern is present
 - *also see 9.6 Mobility, Movement and Joints, 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.8 Pain Management, 9.5 Insomnia, 9.1 Bladder and Bowel Management, 9.3 Cognition*

Area of Specialist Support and Links

- 3.10. The [Neurologist](#) is a medical specialist who specialises in disorders of the nervous system including MND. The neurologist
- coordinates the tests you need for diagnosis and makes the diagnosis of MND
 - monitors the progress of the disease and management of your symptoms
 - reviews and prescribes medications and treatments
 - makes referrals to other specialists and allied health professionals
 - *also see below 9.6 Mobility, Movement and Joints, 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.8 Pain Management, 9.5 Insomnia, 9.1 Bladder and Bowel Management, 9.3 Cognition*
- 3.11. The [Respiratory Specialist](#) is a doctor who specialises in disorders of the lungs and breathing. The Respiratory Specialist
- provides advice about breathing
 - assesses and monitors current respiratory status
 - reviews and prescribes medications and treatments including non-invasive ventilation (NIV)
 - *also see below 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.5 Insomnia*
- 3.12. The [Palliative Care Team](#) specialise in interventions that can improve quality of life for people with life limiting conditions including
- assessing a person's needs and symptom management
 - discussing preferences around artificial nutrition and respiratory support and an advance care directive
 - supporting you during the final months, weeks and days at home, in residential care, a palliative care unit or in hospital
 - supporting your carer
 - *also see below 9.7 Nutritional Needs, 9.4 Fatigue, 9.2 Breathing and Secretion/Saliva Management, 9.8 Pain Management, 9.5 Insomnia, 9.1 Bladder and Bowel Management, 9.3 Cognition, 9.9 Psychological and Social Care: including management of anxiety and depression*

4. Assistive Technology/Equipment

- 4.1. Get advice from an Occupational Therapist, Physiotherapist or Speech Pathologist before using or purchasing assistive technology/equipment
- the [Occupational Therapist](#) and [Physiotherapist](#) will recommend aids and equipment to assist you with your day to day activities, including mobility and transfers
 - the [Speech Pathologist](#) will recommend aids and equipment to support communication, swallowing and, together with the Occupational Therapist, computer access.
- 4.2. [FlexEquip](#) is a service of Motor Neurone Disease NSW (MND NSW) that provides adults with progressive neurological conditions with assistive technology (aids and equipment) to meet short to medium term needs. Depending on your circumstances, FlexEquip equipment may either be loaned or rented to you.

Area of Specialist Support and Links

- If you are diagnosed with MND, and are not eligible for NDIS, FlexEquip equipment may be loaned to you at no charge for short to medium term use.
- If you are under 65 years old, and an NDIS participant diagnosed with MND or other progressive neurological condition, equipment may be rented to you using the AT rental funds in your NDIS plan.

Equipment stocked includes:

- [armchair](#) - utility and electric raiser recliner
- [bathroom](#) - beside commode, over-toilet aid, shower chair, shower commode, shower stool, toilet surround
- [beds and bed equipment](#) - electric bed, mattress overlay, monkey bar, over bed/chair table
- [communication, computer access and environmental control](#) - portable communication aids, call device, environmental control unit, communication apps, software, modified mouse, mounting system, switches and switch interface
- [mobility](#) - walking frame, manual wheelchair, electric wheelchair, portable wheelchair ramps
- [neck support](#) - headmaster collar
- [pressure care](#) - pressure care cushions, mattress overlays
- [transfer aids](#) - sliding transfer bench, transfer belt, transfer board, turntable, hoist

4.3. Government equipment services

[ACT Health Equipment Loan Service](#) provides some assistive equipment which is available on a short-term loan of three months and the [ACT Health Equipment Scheme](#) provides assistive technology (aids and equipment) to meet longer term needs for people who meet eligibility criteria.

[EnableNSW](#) is the NSW Government service providing assistive technology (aids and equipment) to meet longer term needs for people who meet eligibility criteria.

[Territory Equipment Program](#) (TEP) is the NT Government service providing assistive technology (aids and equipment) to meet longer term needs for people who meet eligibility criteria.

4.4. [Assistive Technology Australia](#) (AT Australia) is an independent Information, education, and advisory centre for assistive technology. They provide product and contact information only. AT Australia does not sell AT products

- [bath](#) and [shower](#)
- [toileting](#) - [hygiene](#), [continence](#), [slipper pan](#), [raised toilet seat](#), [portable toilet bottle](#), [disposable urinal](#)

Area of Specialist Support and Links

- [beds](#) and bed equipment - [elevating back rest](#), [bed wedge](#)
- [seating](#) - [utility](#) and [orthopaedic chair](#)
- [environmental control](#)
- [household aids](#)
- [wheelchairs](#), [scooters](#), [cushions](#) and [ramps](#)
- [lifting, transferring and standing](#) and [mobility](#)
- [communication](#) and [computer access](#)
- [eating and drinking](#) - including modified diets, fluids, cups, straws, cutlery and plates
- [clothing and dressing](#)

4.5. Equipment for tube feeding/home enteral nutrition through referral to [Dietitian](#)

5. Home Modifications

5.1. Contact an [Occupational Therapist](#) before starting home modifications for a home environment assessment, design regulatory standards and equipment specifications to meet your needs.

- access to property - vertical lift, platform lift, portable platform lift, stair lift, [portable ramp](#), wheeled equipment access/ramp options
- bathroom modifications - level access, adequate circulation space for wheeled equipment, prevent trip risks, [wall mounted basin/vanity](#) to allow for wheeled equipment to access underneath
- toileting including [cistern flush button modification](#) and [bidet options](#)
- grab rails for [shower](#) and [toilet](#)
- taps [lever](#) or [flick mixer](#)
- [door handles](#)
- [sensor lights](#) for indoor and outdoor areas

Area of Specialist Support and Links

6. Planning for Now and the Future

6.1. Medical Information such as reports for specialists, treatment providers, x-ray reports, imaging reports etc. are your information. These reports are about you and you have a right to obtain these reports. Obtain copies of important documents and communicate as you see appropriate to your family/doctor/hospital. [My Health Record](#) is a secure online summary of your health information.

6.2. [Advanced Care Planning](#) includes:

- preparing a [Will](#) which is a legal document that clearly sets out your wishes for the distribution of your assets after your death. Having a clear, legally valid and up-to-date will is the best way to help ensure that your assets are protected and distributed according to your wishes
- appointing a [Power of Attorney](#) which is a legal document appointing a person or trustee organisation of your choice, to manage your financial and legal affairs while you are alive.
- appointing an [Enduring Guardian](#) which is a legal document that allows someone you appoint to make lifestyle, health and medical decisions for you when you are not capable of doing this for yourself. Your Enduring Guardian may make decisions such as where you live, what services are provided to you at home and what medical treatment you receive if you are unable to do this for yourself.
- talking about your wishes and values about medical treatment and interventions. Thinking about making an [Advanced Care Directive](#), which is sometimes referred to as a 'Living Will', that needs to be taken into account before medical treatment decisions are made on your behalf. Different states have different legislation. Discuss with family, [GP](#) and [Social Worker](#)
- Please note: These documents may have different names and require different application processes in the [ACT](#) and [NT](#). Please speak to your MND Advisor or Infoline for further information.

6.3. A [funeral](#) is a ceremony connected with the burial, cremation, or other rite for someone who has died. This can be planned in advance if wished.

7. Financial and Superannuation Advice and Assistance

7.1. Centrelink and Medicare

- 7.1.1. [Carer Allowance](#) is a fortnightly income supplement if you give daily care and attention to someone who has a disability, serious illness, or an adult who is frail and old
- 7.1.2. [Carer Payment](#) is an income support payment if you give constant care to someone who has a severe disability, illness, or an adult who is frail and old
- 7.1.3. [Carers Supplement](#) is a yearly payment if you care for a person with a disability or serious illness

Area of Specialist Support and Links

- 7.1.4. [Continence Aids Payment Scheme](#) can help you meet some of the costs associated with continence and continence related products
- 7.1.5. [Disability Support Pension](#) is financial help if you have a permanent physical, intellectual or psychiatric condition that stops you from working
- 7.1.6. [Essential Medical Equipment Payment](#) is an annual payment to people who experience increase in home energy costs from the use of essential medical equipment to manage their disability or medical condition
- 7.1.7. [Mobility Allowance](#) is a regular payment to help with essential travel costs if you have a medical condition and can't use public transport
- 7.1.8. [Rent Assistance](#) is a regular extra payment if you pay rent and get certain payments from Centrelink
- 7.1.9. [Sickness Allowance](#) is an income support payment if you can't work or study temporarily because of illness, injury or disability
- 7.1.10. [Telephone Allowance](#) if you have a telephone connected in you or your partner's name and you get certain payments from Centrelink

7.2. Financial Advice and Superannuation

- 7.2.1. Seek [financial advice](#) or consult your accountant/financial planner on how you should manage your assets including shares, bank accounts and property
- 7.2.2. [Early access to Superannuation](#), if you have a medical condition causing permanent incapacity or likely to result in your death within the next 24 months. Find out about tax implications and your choices if your superannuation fund does not offer early access, such as rolling over to another superannuation fund. You may also have insurance policies included with your superannuation, such as income protection and total & permanent disability cover.

8. Travel, Transport and Leisure

- 8.1. There are medical standards for [driving](#) that drivers must meet to ensure their health status does not increase the risk of a crash in which they or other road users may be injured.
- 8.2. Read about things to consider if you are thinking about vehicle modifications, purchasing a vehicle or driving with a disability [Spinal Cord Injuries Association](#) and [Muscular Dystrophy NSW](#)
- 8.3. [Australian Mobility Parking Scheme](#) provides a permit to park in disabled parking spaces and other parking permissions that vary state to state. There is a medical component that needs to be completed for the application
- 8.4. [Taxi Transport Subsidy Scheme](#) provides support for residents who are unable to use public transport because of a disability. The subsidy covers a percentage of the total fare with a maximum subsidy per journey. There is a medical component that needs to be completed for the application

Area of Specialist Support and Links

- 8.5. [Isolated Patients Travel and Accommodation Assistance Scheme \(IPTAAS\)](#) provides some financial assistance if you have to travel more than 100km to access specialist medical treatment and you meet eligibility requirements
- 8.6. [Disabled toilet access key](#) (MLAK Key) enables people with disabilities to gain 24-hour access to a network of public facilities
- 8.7. [National Public Toilet Online Map and Smartphone App](#) provides information on over 16,000 publicly available toilets across Australia, including accessibility, opening hours and facilities
- 8.8. [Companion Card](#) is issued to people who have a significant disability to allow them to participate in community-based activities. The Companion Card allows a person's carer free entry into participating venues and events. There is a medical component that needs to be completed for the application.
- 8.9. [Travel Insurance](#) is offered by many insurance companies but some will not insure people if they have MND. Investigate insurance policies and ask MND Infoline for the latest feedback. Some have found suitable insurance through [Insureandgo](#). You need to disclose your medical condition before taking out a policy.

9. Symptom Management

9.1. Bladder and Bowel Management

- General Practitioner and community nurses for management and medication options.
- Occupational Therapist and Physiotherapist for positioning, aids and equipment.
- Dietitian for fluid and fibre intake advice.
- [Continence Foundation of Australia](#) and National Continence Helpline.
- [BrightSky](#) and [Independence Australia](#) for advice, samples and products.

9.2. Breathing and Secretion/Saliva Management

- Medical including General Practitioner, Palliative Care Specialist, Neurologist, Respiratory Specialist for positioning and environmental advice, non-invasive ventilation (NIV) such as BiPAP, medications for reducing saliva production, medications to assist with anxiety and laryngospasm, mouthcare.
- Occupational Therapist for positioning and environmental advice.
- Physiotherapist for positioning and environmental advice, assisted cough, relaxed breathing, techniques, secretion clearance management.
- Speech Pathologist for saliva management advice and mouthcare.

9.3. Cognition

- Medical including General Practitioner, Palliative Care Specialist, Neurologist, Neuropsychologist for review and advice.
- Occupational Therapist and Psychologist for advice and strategies to manage cognitive change.

Area of Specialist Support and Links

9.4. Fatigue

- Medical including GP and Respiratory Specialist for review and advice.
- Occupational Therapist and Physiotherapist for energy conservation strategies and aids to assist with activities of daily living.

9.5. Insomnia

- Medical including General Practitioner and Respiratory Specialist for review and advice.
- General practitioner for sleep hygiene strategies and medication.
- Occupational Therapist and Physiotherapist for positioning and comfort in bed.
- Social Worker and Psychologist to discuss anxieties and concerns.

9.6. Mobility, Movement and Joints

9.6.1. Physiotherapist

- baseline mobility and function review and ongoing mobility and transfer review
- trip hazard review and fall prevention strategies
- walking aids and footwear advice
- neck collar for weak neck muscles and positioning
- individual exercise program - strengthening or stretching
- hydrotherapy program - water based program for therapy, rehabilitation, exercise, relaxation and more
- liaison with massage therapist - to manage pain and tightness
- orthotic review for foot drop/shoulder subluxation and/or other splinting - ankle foot orthosis/foot up, positioning in bed

9.6.2. Occupational therapist

- strategies and equipment prescription to assist with maintaining independence with daily tasks including toilet aids, shower equipment, kitchen aids and utensils, dressing aids, home environment strategies
- strategies and equipment prescription to assist with maintaining mobility including walking frame, wheelchair (manual/power) and ramps
- strategies and equipment prescription to assist with maintaining comfort including armchair, bed and bed equipment, neck support and pressure care
- fall prevention strategies
- call alert/personal alarm information

9.6.3. Medical (including General Practitioner, Palliative Care Specialist, Neurologist)

- medication for cramps or pain

Area of Specialist Support and Links

9.7. Nutritional Needs

9.7.1. Dietitian

- advice about eating and drinking enough to maintain weight, energy levels and enjoyment of food
- advice about symptoms that may affect eating and drinking
- guidance on nutritional supplements and tube feeding

9.7.2. Speech Pathologist

- advice on strategies to assist with swallowing including diet/fluid modification such as food and drink thickeners, positioning advice, compensatory techniques.
- advice about saliva management and mouthcare
- aids and equipment to assist with eating and drinking

9.7.3. Other resources

- MND UK - [Eating and drinking with MND](#)
- [supplement suppliers and other resources](#)

9.8. Pain Management

9.8.1. Medical (including General Practitioner, Palliative Care Specialist, Neurologist)

- exclude other causes of pain
- pain management advice and medication

9.8.2. Physiotherapist

- stretching program
- splinting and positioning
- liaison with massage therapist (to manage pain and tightness)
- referral to hydrotherapy

9.8.3. Occupational Therapist

- positioning and pressure care management
- aids and equipment for comfort
- other environmental issues including heating and cooling

9.9. Psychological and Social Care: including management of anxiety and depression

9.9.1. Medical (including General Practitioner, Palliative Care Specialist, Neurologist)

- review to exclude other causes
- referral for counselling support
- medication

9.9.2. Psychologist

- assesses, diagnoses and treats mental health problems
- provides general and specific counselling

9.9.3. Social Worker

- emotional support for person, family and carer

Area of Specialist Support and Links

- information and links to other services and organisations include respite services
 - helps with important conversations such as talking with children, planning for the future
- 9.9.4. MND Support Groups for people who have MND, their family and support network. Often, a guest speaker is invited to share their expertise in a topic that may be of interest to the members of the group. The members themselves meet and share information that may assist others.
- 9.9.5. [MND NSW Carer Support](#) provides information, support groups, education and other service information.
- 9.9.6. [Carer Gateway](#) is a Government service that provides practical information, respite services, counselling and resources to support carers.
- 9.9.7. [Carers NSW](#), [Carers ACT](#) and [Carers NT](#) provide carer specific information, resources, training and a range of carer support groups.
- 9.9.8. [National Carer Counselling](#) via Carer Gateway.
- 9.9.9. [Emergency and short-term respite](#)
- if you need a break or are unexpectedly unable to continue to care for someone.
- 9.10. Speech and Communication Needs**
- 9.10.1. Speech Pathologist
- baseline assessment of communication
 - strategies to assist with intelligibility including psychological support
 - discussion, assessment and customisation of communication aids including voice banking and alternate and augmentative communication options
 - advice about low and hi-tech technology to assist with communicating if speaking becomes difficult.
- 9.10.2. Occupational Therapist
- hands free computer access
 - seating and positioning
 - wrist supports
 - switches/pointers
 - mobile arm supports and tables
- 9.11. Swallowing**
- 9.11.1. Speech Pathologist
- baseline assessment for swallowing
 - advice on strategies to improve safety of swallow including diet/fluid modification
 - regular reviews of swallow function

For more information contact

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Publication feedback - MND NSW welcomes suggestions from people using this document so that it can be improved over time.

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