

When you are living with motor neurone disease (MND), you may be thinking about whether to keep working. This guide is designed to help you make informed decisions about employment.

Employment and MND covers the following topics:

- understanding how MND impacts employment
- things to consider when making your decision
- understanding your workplace rights
- understanding your responsibilities related to living and working with a life-limiting condition
- understanding your financial entitlements including superannuation
- resources that can support you.

### Employment and MND: about the series

MND can affect many aspects of a person's life, including work. This guide is one of a series that provides information about managing employment and MND. There is also a guide for carers, and one for employers.

## How MND impacts employment

Many people are still in paid employment when they are diagnosed with MND. Individual or workplace adjustments can help you maintain productive and fulfilling employment for as long as possible. Reasons to stay employed include:

- financial reasons or family responsibilities
- identity and sense of purpose
- independence
- motivation
- routine
- maintaining important relationships and connections to community.

The impact that MND has on your working role depends on several factors:

- symptoms
- the type of work
- type of tools or equipment needed in a role
- specific duties of the role
- working environment.

Some of the symptoms that may impact your ability to work include:

- mobility changes
- limb weakness
- changes in speech or communication
- saliva control
- fatigue
- emotional lability (when emotional responses are different to how you feel).

Some other, less obvious changes may also impact roles at work, including anxiety, depression or mild cognitive changes.

An MND diagnosis can raise many work-related questions. Look for the table, **Who Can Offer Support** at the end of this guide to find out more.



## Making decisions about work

It's a good idea to seek relevant health, financial and legal guidance before making any decisions about work. However, the progressive nature of MND will likely affect your ability to work at some stage. Regardless of whether your symptoms are currently impacting your work, you may have questions about your future employment.

These might include:

- Should I tell my employer I have MND?
- Should I adjust my work hours?
- Will I be able to manage my current duties?
- Should I take an early retirement or voluntary redundancy?
- Will I be able to support my family?

It can feel overwhelming to make decisions about work while coming to terms with a diagnosis of MND and managing symptoms. Making informed decisions will ensure you are able to prolong your working role and manage your future financial security.

## Communicating with your employer

There is no legal obligation to tell your employer about your MND.

However, you need to disclose your MND to your employer in the following situations:

- if your MND symptoms are impacting on your work duties or putting you or others at risk
- if you have been asked to complete a pre-employment medical check and your MND symptoms could impact the proposed work duties or put you or others at risk.

In many circumstances, disclosing your MND diagnosis to your employer can be a practical and positive step.

Talking to your employer about MND can assist by:

- explaining any obvious changes
- minimising the stress of trying to disguise symptoms
- allowing for conversations about adjustments to optimise productivity and safety.

Importantly, if you do not disclose your MND diagnosis to your employer and it leads to a workplace injury, you may not be entitled to compensation under some state-based compensation schemes for that injury.



# Reasonable adjustments

It is illegal for an employer to treat an employee (or job applicant) differently because they are living with MND. If they do, this is discrimination. Also, employers are required to take 'reasonable' steps or adjustments to support you.

**Some examples of reasonable adjustments include:**



**Flexible work hours**



**Working from home**



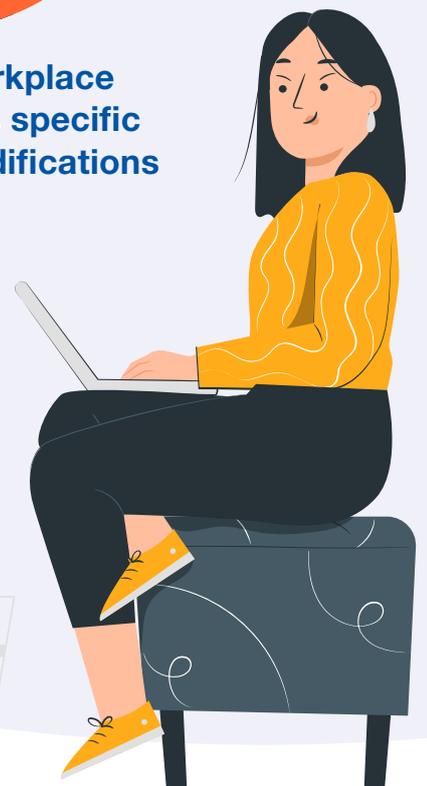
**Allowing more breaks**



**Altering performance requirements**



**Supporting workplace changes such as specific equipment or modifications**



Employers may be able to apply for funding towards necessary workplace modifications or equipment through the Employment Assistance Fund. Employees or employers can explore this Australian Government funding initiative, and other employment support options by calling 1800 464 800 or through the Job Access website [jobaccess.gov.au](http://jobaccess.gov.au)

# Understanding financial entitlements

You may be thinking about exploring options for flexible hours, job-sharing, and other adjustments to stay productive in your role and manage your health. However, you should seek appropriate legal and/or financial advice before you make any changes to your regular working hours. Some changes may impact your access to certain employment benefits, insurances or superannuation entitlements.

Understanding your entitlements can help with future plans and financial preparation. If you are self-employed and making decisions about your future, seeking early financial and or legal advice is also a good idea.

## Superannuation

If you are working and have superannuation (or 'super') you will likely have disability insurance benefits. You can claim on these benefits if illness or injury impacts work capacity or life expectancy.

There are a few specific questions you can ask your superannuation provider about your entitlements following your MND diagnosis.

Questions to ask include:

- Am I eligible for a total and permanent disability (TPD) claim?
- What documentation do I need to support my claim? (e.g. medical evidence)
- When should I lodge my claim?
- Do you offer terminal illness benefits? If so, what are the eligibility criteria?
- Do I have an insurance policy as part of my account? (e.g. income protection, death cover)

Some of these options may allow faster access to your super with different tax implications.

Your entitlement to insurance benefits may be affected if you reduce your hours, so seek advice before changing your work hours or duties. Your superannuation statement will usually include information about your superannuation-based insurance entitlements.

Your super fund may also have compassionate release, terminal illness or permanent incapacity provisions that allow early access to your superannuation for specific expenses.

Ask for written information about all available options and consider requesting a meeting with a fund representative. Talking to someone about your specific situation may help you to understand your full range of entitlements. This can make a significant difference to your financial security during this time.

## Other insurance

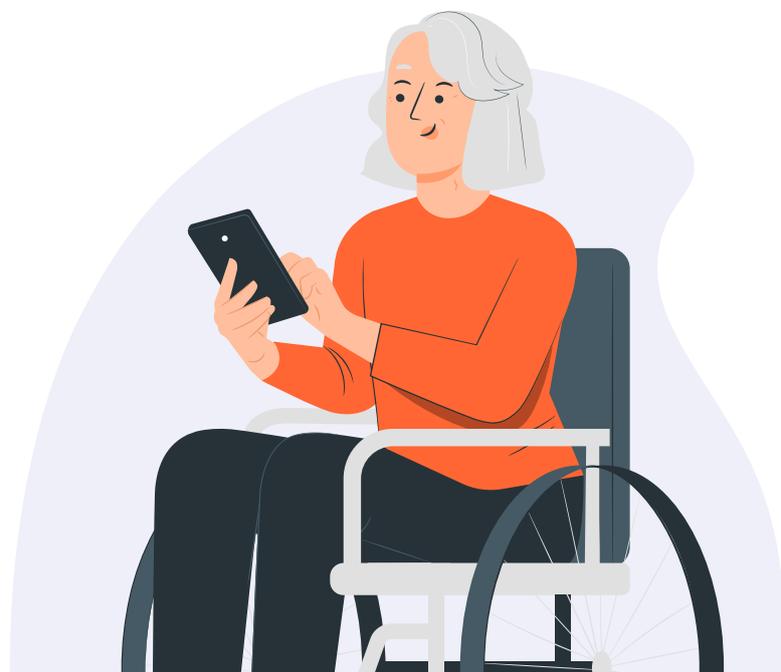
You may have disability insurance entitlements outside of superannuation. This could include those:

- bought directly from an insurer
- arranged with the help of a financial planner or advisor
- provided as part of your employment.

If you are employed, it's a good idea to check your employment contract and talk with your Human Resources (HR) team to find out what benefits are available.

As with the insurance benefits in super, these benefits usually provide payments in specific circumstances, including:

- terminal illness
- being forced to stop work due to illness or injury (TPD and income protection)
- death.



# Managing your symptoms at work

Everyone experiences MND differently: symptoms occur at a different rate, and in a different order. However, some of the following ideas may help with managing symptoms at work.

Before you make any adjustments, seek advice as to whether changes to your employment will impact your super/ insurance benefits.

## Role adjustments

Adjustments to how you work, the equipment or workstation you use, or the broader workplace environment can help you to continue your role. Talk to your employer about adjusting tasks or modifying duties to accommodate your changing needs. You might also discuss if there are different tasks within your skill set that you can do.

Consider the physical demands of your role, whether it requires the following:



**Physical strength**



**Repetitive movements**



**Fine motor skills**



**Prolonged sitting, standing or awkward positions**



## Conserve your energy

Take regular rest breaks, allow more time to complete tasks, schedule complex tasks or meetings when feeling at your best (eg. in the morning before you start feeling tired).

## Ask an occupational therapist (OT)

An OT may be able to suggest opportunities for maintaining current roles and responsibilities through workplace modifications, assistive technology or other useful ideas.

## Ask a speech pathologist

Changes in speech and saliva control may impact telephone and office conversations. It can also affect your confidence. A speech pathologist may offer strategies or assistive technology to help manage speech and swallow challenges.

## Look after your mental health

People living with MND may experience changes in mood such as anxiety or depression. These mental health challenges can impact your focus, problem solving, time management and social interactions. Speak to your employer about whether they have an Employee Assistance Program (EAP) that offers counselling services. You may also be eligible to obtain a Mental Health Treatment Plan. These can provide a certain number of Medicare-subsidised mental health support sessions per calendar year. A referral from a General Practitioner (GP) is required.

## Disease progression

As MND progresses and symptoms have greater impact, it is likely that further adjustments and reviews will be required. Your medical and allied health team can give advice about extra support that may prolong your working role.

## Who can offer support

Role	Support they can offer
<b>Neurologist</b>	A neurologist may assist with required forms for employers, insurance companies, or government agencies that need medical verification of the condition and its impact on work capacity. A neurologist may be able to provide details on the type of MND a person is living with, likely progression and development of symptoms.
<b>Allied Health Therapists</b>	Allied health professionals like OTs, physiotherapists and speech pathologists can give information and support, and help you make informed decisions about work. They can assess your functional ability and give practical solutions. Allied health professionals can support realistic long-term planning that balances work with safety and quality of life, which might extend your working life.
<b>Financial Advisor</b>	A financial advisor can analyse your financial situation and model different scenarios to support you to make informed decisions about work.
<b>Lawyer</b>	<p>A lawyer can help you understand your rights based on relevant national and state-based laws. They can help you understand the following:</p> <ul style="list-style-type: none"> <li>• disclosure requirements</li> <li>• when discrimination has occurred</li> <li>• what counts as a ‘reasonable adjustment’</li> <li>• whether denial of adjustments is lawful</li> <li>• communicate with your employer on your behalf.</li> </ul> <p>They can also give advice about your superannuation-based or other insurance entitlements and when they can be claimed.</p>
<b>Family/ loved ones</b>	Family members and loved ones can be an important source of emotional and practical support. Family members often provide valuable insight into functional changes they observe at home that you might not be aware of. This can help make sure any decisions about work are realistic. See <i>Employment and MND: for carers</i> for more information for family and friends.
<b>MND Advisor</b>	MND advisors have specialised knowledge of MND progression and symptoms and can support conversations around employment plans. While they cannot offer advice around financial or employment decisions, they may be able to direct you to service providers who specialise in this area.

## Services and support

**MND Info Line**

**1800 777 175**

9am to 4.30pm Monday to Friday

**mndconnect.org.au**



### Other guides in this series

- Employment and MND: for carers
- Employment and MND: for employers



## Other useful websites

### Employment Rights and Workplace Flexibility

#### Job Access

1800 464 800 | [jobaccess.gov.au](http://jobaccess.gov.au)

#### Fair Work Ombudsman

13 13 94 | [fairwork.gov.au](http://fairwork.gov.au)

#### Australian Human Rights Commission

1300 656 419 | [humanrights.gov.au](http://humanrights.gov.au)

### Entitlements

#### Services Australia

[servicesaustralia.gov.au](http://servicesaustralia.gov.au)

#### ATO (Early Access to Superannuation)

[ato.gov.au/individuals-and-families/super-for-individuals-and-families](http://ato.gov.au/individuals-and-families/super-for-individuals-and-families)

#### Superannuation & insurance law glossary of terms

[berrillwatson.com.au/expertise/glossary](http://berrillwatson.com.au/expertise/glossary)

### Equal Opportunity and Human Rights Commissions

#### ACT Human Rights Commission

[hrc.act.gov.au](http://hrc.act.gov.au)

#### Anti-Discrimination NSW

[antidiscrimination.nsw.gov.au](http://antidiscrimination.nsw.gov.au)

#### NT Anti-Discrimination Commission

[adc.nt.gov.au](http://adc.nt.gov.au)

#### Queensland Human Rights Commission

[qhrc.qld.gov.au](http://qhrc.qld.gov.au)

#### Equal Opportunity Commission South Australia

[equalopportunity.sa.gov.au](http://equalopportunity.sa.gov.au)

#### Equal Opportunity Tasmania

[antidiscrimination.tas.gov.au](http://antidiscrimination.tas.gov.au)

#### Victorian Equal Opportunity and Human Rights Commission

[humanrights.vic.gov.au](http://humanrights.vic.gov.au)

#### Equal Opportunity Commission WA

[wa.gov.au/organisation/equal-opportunity-commission](http://wa.gov.au/organisation/equal-opportunity-commission)



until there's a cure, there's care

### **MND Australia**

[mndaustralia.org.au](http://mndaustralia.org.au)

[info@mndaustralia.org.au](mailto:info@mndaustralia.org.au)

(02) 8287 4980

### **State MND Associations**

To contact the MND Association in your state call the MND Info Line 1800 777 175

#### **MND New South Wales**

[mndnsw.org.au](http://mndnsw.org.au)

[admin@mndnsw.org.au](mailto:admin@mndnsw.org.au)

#### **MND Queensland**

[mndqld.org.au](http://mndqld.org.au)

[info@mndqld.org.au](mailto:info@mndqld.org.au)

#### **MND South Australia**

[mndsa.org.au](http://mndsa.org.au)

[admin@mndsa.org.au](mailto:admin@mndsa.org.au)

#### **MND Tasmania**

[mndatas.asn.au](http://mndatas.asn.au)

[info@mndatas.asn.au](mailto:info@mndatas.asn.au)

#### **MND Victoria**

[mnd.org.au](http://mnd.org.au)

[info@mnd.org.au](mailto:info@mnd.org.au)

#### **MND Western Australia**

[mndawa.asn.au](http://mndawa.asn.au)

[admin@mndawa.asn.au](mailto:admin@mndawa.asn.au)

#### **ACT and NT contact:**

[mndnsw.org.au](http://mndnsw.org.au)

[admin@mndnsw.org.au](mailto:admin@mndnsw.org.au)

## Acknowledgements

The Employment and MND guides were developed by MND Victoria in consultation with MND Australia and Tom Cobban, Berrill & Watson Lawyers.



We are proudly delivering projects for the Peer Support and Capacity Building (PSCB) grant for the NDIS. Together we're ensuring people with disability access supports to build skills and connect with others who have similar experiences.

This guide provides general information to help you understand your work rights and entitlements after an MND diagnosis. However, everyone's situation is unique and laws can change over time. We encourage you to speak with professionals who can give you advice tailored to your specific circumstances—this might include contacting the Fair Work Ombudsman (13 13 94), Services Australia (132 717), or seeking legal, financial, or medical advice. Please always double-check the latest details with official sources before making important choices about your employment and entitlements.