

As a carer for someone living with motor neurone disease (MND), your ability to stay working may be impacted. There are steps you can take to manage both your caregiving and employment responsibilities.

Staying employed while caring for someone else provides several potential benefits for you and the person you are caring for:

- financial
- social support
- respite from the daily tasks associated with caring.

The following information can assist carers make decisions about their employment while caring for someone living with MND.

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 people living with MND, and one for employers.

Communicating with your employer

It is up to you whether you feel comfortable telling your employer about your caring role. If you do decide to share this information, you can give as much or as little detail as you like.

To help you prepare for any discussions, consider the following:

- check workplace policies about leave entitlements
- understand your rights and entitlements.

Many employers are willing to offer flexible work arrangements. These might include flexible hours, remote work, or additional leave options.

Understanding your rights

You have rights as a carer. Seek out any available carer's leave or entitlements under your workplace's policies. In Australia, carers may have the right to request flexible working arrangements under the Fair Work Act.

Discrimination and MND

It is illegal for an employer to treat an employee (or job applicant) differently because they are living with MND or caring for someone 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
- altering performance requirements
- allowing more breaks
- working from home.



Leave entitlements

Sick leave (personal/carer's leave)

Full time employees in Australia have access to 10 days a year of paid sick or carer's leave. This builds over time and can be used to care for immediate family members or household members who are ill or injured.

It is recommended you give your employer as much advance notice as possible when taking sick or carer's leave. An employer may ask for evidence to support the leave application. This is typically a medical certificate or other relevant documentation. However, some enterprise bargaining agreements restrict employers requesting this.

Employers cannot refuse a legitimate application for sick or carer's leave if it follows the guidelines stated in the Fair Work Act 2009 (e.g. is for an immediate family member, member of the household who requires care etc).



Compassionate leave

An employee may be entitled to a period of paid compassionate leave each time a member of their immediate family or household is diagnosed with a life-threatening illness or injury. This is in addition to regular carer's leave. Casual workers have the right to receive unpaid compassionate leave.

Money matters

Financial entitlements

Understanding your entitlements helps you to plan for the future.

You may be interested in exploring options for flexible hours, job-sharing, and other adjustments to support your caring role. 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.

If you are self-employed, seek financial and/or legal advice before making decisions.

Carer payments

A person caring for someone living with MND may be able to access government benefits, which can provide financial support during this time. The primary payments available are:

- **Carer Payment:** for those providing constant care to someone with disability or medical condition.
- **Carer Allowance:** payment if you provide daily care for someone with a disability or medical condition.
- **Carer Supplement:** annual payment for those receiving the Carer Allowance or Carer Payment.

To explore eligibility, conditions and to apply for these payments, please visit Services Australia servicesaustralia.gov.au

Seeking support

Support systems are available to help you manage stress and maintain your wellbeing. Your workplace may offer an Employee Assistance Program (EAP), or you might consider joining a carer support network. These resources can provide valuable guidance and emotional support. See below for more detail.

Carers may also be eligible to obtain a Mental Health Treatment Plan. These can provide a certain number of mental health support sessions per year, partly or fully paid by Medicare. A referral from a General Practitioner (GP) is required.

“MND brings new changes almost daily, on top of an already busy life. Getting support and advice about work just makes sense – don’t do it alone, there’s help available.”

Andrea Salmon
Carer Program Coordinator
MND Victoria

Plan ahead

MND is a progressive condition. It’s a good idea to consider how your caregiving role may evolve as the condition progresses. This includes thinking about how you can balance your caring responsibilities with your work. Planning ahead can help you manage changes more effectively.

Other guides in this series

- Employment and MND: for people living with MND
- Employment and MND: for employers



Services and support

MND Info Line

1800 777 175

9am to 4.30pm Monday to Friday

mndconnect.org.au



Other useful websites

Employment Rights and Workplace Flexibility

Job Access

1800 464 800 | jobaccess.gov.au

Fair Work Ombudsman

13 13 94 | fairwork.gov.au

Australian Human Rights Commission

1300 656 419 | humanrights.gov.au

Employer Advisory Service

smallbusinessfairwork.gov.au/employer-advisory-service

Entitlements

Services Australia

servicesaustralia.gov.au

ATO (Early Access to Superannuation)

ato.gov.au/individuals-and-families/super-for-individuals-and-families

Superannuation & insurance law glossary of terms

berrillwatson.com.au/expertise/glossary

MND Associations

MND NSW, ACT, NT mndnsw.org.au

MND QLD mndqld.org.au

MND SA mndsa.org.au

MND Tasmania mndatas.asn.au

MND Victoria mnd.org.au

MND WA mndawa.asn.au

Equal Opportunity and Human Rights Commissions

ACT Human Rights Commission

hrc.act.gov.au

Anti-Discrimination NSW

antidiscrimination.nsw.gov.au

NT Anti-Discrimination Commission

adc.nt.gov.au

Queensland Human Rights Commission

qhrc.qld.gov.au

Equal Opportunity Commission South Australia

equalopportunity.sa.gov.au

Equal Opportunity Tasmania

antidiscrimination.tas.gov.au

Victorian Equal Opportunity and Human Rights Commission

humanrights.vic.gov.au

Equal Opportunity Commission WA

wa.gov.au/organisation/equal-opportunity-commission

Carer Supports

Carer Gateway

carergateway.gov.au

Carers Australia

carersaustralia.com.au/about-carers/carers-inthe-workplace

Acknowledgements

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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.