



# Guide for employers of people diagnosed with motor neurone disease

## What is motor neurone disease (MND)?

- MND is a progressive and terminal disease, for which there is no cure.
- MND is an umbrella term covering many different types of MND.
- The type of MND your employee has will determine their initial symptoms. These could be:
  - weakness in the arms or legs
  - weakness in the muscles of speech and swallowing
  - weakness in the muscles that control breathing
  - fatigue.
- Diagnosis often takes a long time due to the wide range of possible symptoms, and the possibility that these symptoms may be characteristic of another disease. As a result, your employee may be struggling with these issues long before they are aware of the future implications and prognosis.
- MND can affect people of any age.
- Most people with MND die within 2 to 3 years but some live for 10 years or more.

## Diagnosis

This is an overwhelming and life-changing event. This person now faces losing their ability to use all voluntary muscles so that in the end they will be unable to walk, talk, eat or breathe on their own. Their future will be cut short, and they need to face the fact that their death will come far sooner than expected.

In the early stages many people diagnosed with MND wish to continue living as normally as possible, and are quite capable of continuing in their employment.

There will come a time when the person with MND is no longer able to work.

## Advice for employers of people diagnosed with MND

Employers can best support their employees diagnosed with MND by engaging in open, confidential communication, providing reasonable accommodations, focusing on the person's abilities, and seeking expert advice from support organisations.

- **Avoid assumptions:** It is best not to make assumptions about the employee's needs, capabilities, or how their condition will progress. The individual is the expert on their own disability.
- **Maintain open communication and confidentiality:** Foster an environment of trust where the employee feels comfortable discussing their changing needs. Discussions about an employee's health status are personal and should remain confidential.
- **Focus on abilities:** Concentrate on what the employee can do and what accommodations would help them be productive, rather than focusing on the limitations imposed by the condition.
- **Offer more frequent or longer breaks** to manage fatigue.
- **Implement reasonable accommodations:** Employers are obligated to provide reasonable accommodations to avoid discrimination. These often cost very little and might include:
  - **Flexible working hours** or the option to work from home.
  - **Modifying job duties** or reallocating certain tasks.
  - **Physical adjustments** to the workspace, such as ensuring building accessibility or providing ergonomic equipment (specialised chairs, keyboards, monitors). Even the smallest adjustments such as moving furniture to create a wider passageway or removing tripping hazards will prove very helpful.
  - **Communication adjustments** for employees whose speech is indistinct or who are unable to talk.
    - **Use of a mobile phone** or computer to type out messages and requests.
    - **A pad and pen** can be used for writing messages.
    - **Communication boards** customised with common phrases, requests, or information.
    - **Assistive technology**, such as speech recognition software or screen readers are accessible if appropriate.

NB. Although the person may not be able to speak, they will be able to hear and understand others speaking to them, so please address them as you normally would.

- **Train managers:** Ensure line managers have the skills and confidence to manage a colleague with MND effectively, sensitively and with respect.
- **Maintain social connection:** When an employee is on leave or working reduced hours, it is good to keep in touch about social news and consider inviting them to social functions to maintain a sense of belonging.
- **Plan ahead:** Discuss potential changes to the role and future planning with the employee. This can help avoid disruption and ensure continued productivity for as long as possible.



**Motor Neurone Disease New Zealand** (MND NZ) can offer expert advice and can help identify suitable accommodations. Each MND NZ client is allocated a regional MND Support Advisor who will be able to liaise with the employer if their client has requested and consented to this. For more information, visit [www.mnd.org.nz](http://www.mnd.org.nz)



The Ministry of Social Development website also has [advice on supporting a person with a disability](#) in the workplace.

Where costs are involved, extra support may be available (for example, through a [Workplace Modification Grant](#) or the [Job Support Fund](#)). However, this is not “a given” in the case of motor neurone disease as the employee’s life expectancy is often short.

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