

Psychological wellbeing and care for people living with Motor Neurone Disease (MND) and their carers

Community Resource





Motor Neurone Disease (MND) is a condition that progressively gets worse over time, and sadly, there is no cure. However, treatment and care can help maintain quality of life and manage symptoms. The key is to create a sense of control and independence.

The spouses or children of the person living with MND, usually become their carers. This involves providing physical and emotional support and can be very time consuming. It is important that carers also look after themselves and seek professional support for their own mental and emotional health. A psychologist can help carers work through their grief and other difficult emotions during and after caring for someone living with MND.

What is MND?

Motor Neurone Disease (MND) is a group of rare diseases where a person's nerves are affected, and ultimately leads to death. A person with MND will gradually lose ability to move and control their muscles, which eventually leads to becoming paralysed. People living with MND may feel their arm and leg muscles become weak, and will find it difficult to talk, swallow, eat and breathe. MND can also affect a person's thinking.

Although the speed of progression can vary, these symptoms can get worse very quickly, and people usually live for about 27 months after they have been diagnosed. Most people with MND will eventually stop being able to breathe and pass away 3-4 years after their symptoms start. Some people live longer, and about 10% of people with MND live over 10 years.

MND is not common, and the cause is unknown. MND runs in some families, so genetics may be the cause for about 5-15% of people living with MND. Men are more likely to get MND than women, and MND usually starts when someone is between 50 to 70 years old.

Diagnosis

The symptoms of MND can easily be mistaken for other diseases. Therefore, people are often given the wrong diagnosis, and it usually takes about one year to be correctly diagnosed with MND. People usually have lots of appointments with different health professionals for several months. This experience prior to diagnosis is called "being on a diagnostic roundabout".

Being diagnosed with MND usually happens gradually during several appointments with a neurologist (nerve specialist). Once someone is diagnosed, the news is usually life-changing and devastating.

Impact of MND and the risk of psychological problems

There is no cure for MND, and people living with MND feel a sense of loss, so seeing a psychologist can help them cope. A person with MND faces many physical, social, and financial problems and changes, which can be hard to get used to. When people are diagnosed with MND they may feel angry and frustrated about the long process of being diagnosed, or the way they were given the bad news. It can be helpful to see a psychologist to discuss this and how the diagnosis will impact them.

One of the biggest challenges with MND is the feeling of losing control. Talking with a psychologist and clarifying the results of living with MND can help people accept the condition and make plans. This helps people living with MND to feel in control, as they can choose which treatment options they prefer. It also helps them feel in control to focus on the present and their personal values, as well as maintain a sense of identity. Feeling in control can help improve mental wellbeing.

Muscle weakness

People living with MND often report feeling pain. They also lose strength and muscle control, making it difficult to do things like walking, speaking, eating, and breathing. This means people living with MND need to rely on others for help and are often not able to do things they enjoy. This can cause them to feel hopeless, depressed, and sometimes suicidal.

Breathing issues

People living with MND often have shortness of breath, especially when lying down, and hypoventilation (breathing extremely slowly) is common. These symptoms get worse as time goes on. These symptoms can be scary and cause people to feel distressed. Shortness of breath and tiredness are linked with anxiety, which can lead to lower quality of life and feeling depressed.

Psychologists can help people living with MND cope and decrease anxiety, allowing them to enjoy life more. Non-invasive ventilation helps people breathe and live longer, and psychologists can help people be diligent about using it.

Dysphagia (difficulty swallowing) and complications

Most people living with MND have difficulty swallowing (dysphagia) due to their muscles weakening. This causes weight loss, thirstiness, choking and infection in the lungs, which is the main cause of death for people with MND. People with MND are often very afraid of choking. Eating can be stressful as it takes more concentration and time. Food can become seen as fuel to survive and even seem dangerous. One way to help this is to remove social distractions while eating. However, to reduce isolation, it can be helpful if carers sit quietly while the person with MND is eating. Focusing on the present while eating can help manage the issue of swallowing and reduce stress.



Eventually, people living with MND will need to have surgery to place a feeding tube into their stomach. This is a difficult decision, and people with MND often postpone it as they don't want to lose the option of eating normally. Accepting the reality of the condition sooner means that decision-making can happen faster, although some people living with MND prefer to delay this. Viewing the surgery as something to help maintain life and independence, rather than take this away, helps maintain a sense of control. Speaking to loved ones about these decisions can help improve mental health.

Communication difficulties

Difficulty speaking (dysarthria) is usually one of the first signs of MND and often one of the worst parts of the disease. Speech usually becomes slurred, slow, and hoarse-sounding. Speech loss affects people living with MND's sense of identity, self-consciousness, participation in daily activities, relationships and engagement with health and social care.

People living with MND sometimes use writing or typing when speech is too hard to understand. However, eventually, these options will not be

possible when the muscles in the hand get weaker. People living with MND can use ways to communicate, including low-tech options (e.g., gestures, facial expressions, handwriting, topic and alphabet boards, eye-linking systems) or high-tech options (e.g., tablets with voice-banking outputs). These can help the person feel more in control and independent. For further information about these devices, see the [MND Connect](#) website.

Many people living with MND can have short outbursts of crying or laughing that can be difficult to control. This can be embarrassing and distressing and may lead people living with MND to isolate.

Neuropsychiatric impairments

People living with MND often experience issues in their thinking, including memory problems and difficulty understanding social situations. They may also lose their energy, become less sensitive to others and more self-focused. These issues might lead to depression and hopelessness. Sticking to treatment advice can help people living with MND live longer. Changes in thinking and behaviours are linked to previously having a

mental health condition, especially disorders like depression and anxiety.

Depression and anxiety among people living with MND

As the progression of the disease is so fast and leads to death, those with MND often suffer from depression and anxiety, which can lead to a higher risk of suicide. Females and younger people with MND are more likely to be depressed. When people first hear the news of the diagnosis or just before this, they are more likely to have symptoms of depression and/or anxiety. A sense of loss of independence is also linked to depression and anxiety.

Decision-making

Psychologists and health care professionals can help people living with MND make decisions about which treatments to use to help manage symptoms. It is important that people living with MND can make their own decisions and

have the freedom to choose whether to manage symptoms early on, wait until later, or not use any treatment at all. The benefits of some MND treatments are not very clear, so it is helpful to have a professional to talk to about what is best. It can also be useful to hear from other people living with MND, to discuss the pros and cons of different treatments. A team of health professionals can assist with making decisions about treatment options, end-of-life care, and finances.

It is good to have regular discussions with a psychologist or healthcare professional about options to help with breathing and feeding. These decisions can be emotional, as using interventions can cause people living with MND to feel like they are losing independence, their identity, and normal life.

End-of-life considerations

Due to how fast the illness progresses, it can be helpful to plan ahead about how the symptoms will be managed. This is called advance care planning/yarning (ACP/ACY) and helps the treatment team know the patients' wishes. Talking about end-of-life (palliative) care early can help people living with MND accept the changes and losses they are facing. This also helps people living with MND feel more in-control of their decisions and improves their mental well-being. Some people living with MND do not want to talk about ACP/ACY until later for various reasons, for example, so that they can live in the moment.

People living with MND sometimes wish to hasten death because the symptoms progress so quickly. They might stop wanting treatment or stop eating/drinking. People living with MND are also at higher risk of suicide compared to others who do not have a disease affecting their brain and nervous system. It is common for people to have suicidal thoughts just after being diagnosed and when the symptoms get beyond their ability to cope.

Psychological treatment for people living with MND

Various psychological interventions have been trialled to see whether they help people living with MND. Several of them have been shown to reduce depression and anxiety and improve quality of life. These are some of the psychological interventions that can help people living with MND:

- **MND-tailored Mindfulness-Based Stress Reduction:** This can reduce depression and anxiety and improve quality of life for people living with MND. Meditative training involves focusing on the present moment and managing emotions by accepting them without judgment.
- **Acceptance and Commitment Therapy (ACT):** ACT can help reduce anxiety and depression and improve mental wellbeing. This approach combines acceptance, mindfulness, motivation, and behaviour change techniques. The aim is to decrease unhelpful attempts to control negative thoughts, emotions, physical sensations, and encourage participation in enjoyable activities.
- **Cognitive-behaviour therapy (CBT):** CBT helps people think more helpfully about their situation and choose more helpful behaviours. Studies have shown that it can improve quality of life and reduce depression and anxiety.
- **Psychodynamic hypnosis:** In this therapy, hypnosis is focused on reducing the sense of pain, and improving illness acceptance and ability to cope. An initial trial of this therapy showed that people felt like their pain reduced



and sleep improved. This therapy could also help people manage their emotions and reduce anxiety and depression.

- **Dignity Therapy (DT):** This intervention involves creating a document about the patient's life based on a life-reflection interview. Important memories, achievements, and events are discussed to recognise life's dignity and meaning and reduce distress about death.

- **Expressive disclosure:** This involves either writing or speaking about one's deepest thoughts and feelings related to a person's experience with MND. The idea is that expressing rather than withholding stressful events leads to reduced psychological distress. Results have shown that this could help improve mental wellbeing, especially for people living with MND who have difficulty expressing emotions.

Not everyone with MND is the same, and each person may prefer different types of psychological interventions. However, the key factors needed in therapy for people living with MND are:

1. Assist the person to learn skills to manage negative thoughts and emotions
2. Increase personally meaningful behaviour
3. Re-direct the focus to what can be controlled
4. Increase focus on experiences in the present.



Challenges to carer's psychological wellbeing

Spouses and children of people living with MND often provide most of the care and support. Caring for people living with MND includes physical and emotional support and helping them with decision-making about treatment.

The disease has been described as continuous and exhausting, with no hope for recovery. It takes a lot of time and energy to care for people living with MND so that they can live at home as long as possible. This involves helping people living with MND with activities of daily life, including eating, drinking, showering, etc. Carers usually spend about 9.5 hours per day looking after people living with MND, and this time increases as the disease gets worse.

The mental health and well-being of carers are affected by the wellbeing of the person they care for with MND. So, carers for people living with MND need to look after their own well-being, especially if they are living with a person with MND. The more time spent caring for a person living with MND can lead to increased chances of feeling mentally distressed. Carers can experience depression, anxiety, tiredness, social issues, and are at high risk for grief issues. Low self-esteem and worrying about the person with MND's life ending, and changes to the relationship dynamic can all contribute to distress. However, positive coping strategies and social support can help improve mental well-being and quality of life.



MND carers can experience three types of grief:

- 1) Anticipatory grief:** this is grief prior to the person living with MND passing away, and often starts when the person living with MND is diagnosed.
- 2) Post-death grief:** this is grief after the person living with MND passes away.
- 3) Prolonged grief disorder (PGD):** when the grief lasts a long time after the person living with MND passes away.

Factors that can contribute to all three types of grief include:

- Negative experiences as a carer
- Focusing on the loss
- Not enough support after the person living with MND passes away
- Emotionally avoidant coping style
- Not enough psychological support.

MND carers are more likely to experience PGD if:

- They suffer from depression or anxiety
- Have poor family functioning
- Had another loss within the 12 months prior to the person living with MND passing away
- They were the partner/spouse of the person living with MND
- The person living with MND was under 60 years old
- If the person living with MND passed away in less than 1.5 years
- If the carer experienced anticipatory grief

MND carers often need mental health support in addition to family and social support. Carers require information about MND, as well as coping strategies to manage the changes in the relationship with the people living with MND; and help with planning for after the people living with MND passes away.

Learning about MND can cause distress. So, it is important that carers receive mental health support as well as information about MND. A psychologist can provide this mental health support and help carers cope with their emotions, accept the situation, and manage symptoms of depression and anxiety. It is also recommended that they continue seeing a psychologist after the person with MND passes away.

Carer burden: Carer burden refers to the physical, emotional, social, and financial toll that comes with caring for people living with MND.

Factors linked to higher carer burden include:

- The person living with MND is less able to do things
- The carer has symptoms of depression
- The carer does not get enough information or training about MND
- The carer experiencing a negative impact on other relationships
- Higher number of hours caring for the person living with MND
- Carer has poor problem-solving skills and resilience
- Carer does not have enough social support

A psychologist can help carers review their responsibilities and discuss positive aspects of the role to help reduce the burden.

Factors that can help reduce carer burden include:

- Thinking about positive aspects of caring
- Feeling satisfied
- Doing things outside of caring
- Self-care
- Finding meaning in the caring role
- Having hope.

Psychological interventions for the carers of people living with MND

There is not much research about therapy for MND carers, although some initial studies have found that the following treatments can be helpful:

- **Mindfulness:** Mindfulness can include training to meditate and focus on the present. This can help improve mental well-being, relaxation, the ability to manage emotions, and acceptance. Mindfulness could also help reduce carer burden and improve energy.
- **CBT:** Cognitive behavioural therapy (CBT) helps people think more helpfully about their situation and choose more helpful behaviours. CBT could help improve quality of life and reduce carer burden.
- **Self-disclosure and human development:** Exploring the meaning of the carer's role and having the chance to speak about and process emotions can help improve well-being.
- **Support group:** A support group for family carers can help family members, especially children of people living with MND, cope with the situation. A support group can also help carers not feel alone and feel more able to handle the caring role.
- **Training for youth carers:** Youth carers of people living with MND are usually more isolated and don't get as much MND carer training. So, attending training can help improve confidence and competence in the caring role.

The importance of addressing individual needs in carer interventions

MND carers often feel like they do not have enough support or acknowledgement. They sometimes find that healthcare providers and friends/family don't understand or support them enough. So, it can be helpful for MND carers to see a psychologist.

The Australian MND Advisory service provides a person-centred care model to support carers. This service offers practical and emotional support and helps carers feel more able to make decisions about their own wellbeing.

The needs of the MND carer can vary according to the progression of the disease. MND carer needs can be grouped into 4 different stages:

- 1) Early coping and adjustment after diagnosis:** Carer needs in stage 1 include gaining information about the diagnosis, and how to cope with it.
- 2) Across the caregiving course:** Carer needs in stage 2 include gaining information, emotional support, formal support with care at home, financial support, information about what people living with MND can eat, as well as role and social changes.
- 3) Transition to the terminal stage:** In stage 3, carers need information and access to services, meetings with healthcare practitioners, information about coping with losing their loved one, and how to use assistive technology.

4) Coping with change and loss after

bereavement: In stage 4, carers need access to grief support.

Carers can feel stressed if the person living with MND does not want to co-operate or receive help from services. This means that the person living with MND is mainly relying on the carer and not other services, which can increase the burden on carers.

The individual needs of each MND carer may vary. Healthcare professionals may use tools such as questionnaires to identify the needs of MND carers at each stage of disease progression. These tools may be used regularly as the carer's needs may change as the disease

usually progresses quickly. This can help carers to be prepared and have plans and solutions in place as problems arise. Regularly reviewing an MND carer's needs can help address problems before they become overwhelming.

The needs of MND carers are all different. This means that it can be helpful to find out your specific needs and address them. Seeing a psychologist can help with this. It is important that psychologists help the person with their feelings as well as their ability to function, and include support for the carer's self-acceptance, personal growth, positive relationships, purpose in life and autonomy.



More information

[MND Australia](#)

MND Australia is the national peak body of state organisations that support people living with MND, their carers and family. MND Australia has a national free call information line 1800 777 175 mndaustralia.org.au

Each state has its own MND Association that provides information and various forms of support for people living with MND, their carers and families. Services include MND Advisors, MND support coordinators, education sessions, health professionals, access to equipment and assistive technologies, and support groups.

These services and their contact details can be found at: mndaustralia.org.au/mnd-connect/find-services/state-mnd-associations

[MND Connect](#)

MND Connect provides specialist MND information and resources for people living with MND, their carers and family.

mndaustralia.org.au/mnd-connect

[FightMND](#)

FightMND's purpose is to find effective treatments and ultimately a cure for motor neurone disease. FightMND also raises funds to provide various forms of support to people living with MND, their carers and families.

fightmnd.org.au

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