



Managing Fatigue

with motor neurone disease

This Booklet Covers:

- Understanding Fatigue and MND
- Early Strategies to Help With Fatigue
- Equipment to Assist With Fatigue
- Local Equipment Services
- Non-Invasive Ventilation (NIV)
- Importance of Seeking Support Early

Understanding Fatigue and MND

Fatigue is a common symptom of MND. It can affect individuals at any stage of the disease and may fluctuate daily.

It extends beyond ordinary tiredness, impacting both the physical and mental abilities of someone living with MND. Fatigue can arise for several reasons, including, but not limited to:

Reduced Muscle Function

As muscle function declines, individuals with MND may find that performing even simple movements requires more force and energy, making daily tasks more exhausting.

Poor Sleep

When someone is experiencing significant fatigue, finding a comfortable position in bed or falling asleep can be more difficult. Insufficient rest and disrupted sleep can make fatigue worse.

Cognitive Effort

For someone with MND, moving the body or preparing for daily activities may require more concentration and planning skills, which can increase fatigue due to the extra mental effort required. Some people with MND may also experience changes in mood such as anxiety, depression or apathy. These changes may also impact on energy levels, concentration and motivation, making daily activities more challenging.

Respiratory Changes

If MND affects breathing, each breath may require more energy than before, gradually increasing overall fatigue.

Effort of Eating

Buying groceries, preparing food, and eating can be exhausting. This may lead to reduced food intake, potentially causing malnutrition and worsening fatigue.

Communication Changes

If someone is experiencing communication changes, such as a softer voice, they may require more energy to speak or communicate, which can further contribute to their fatigue.

Early Strategies to Help With Fatigue

Numerous strategies can be implemented early - even before consulting a health professional - to help manage fatigue, including:

Pacing Strategies

To manage fatigue during activities such as cleaning, walking the dog, or working, it can be helpful to schedule short, regular rest breaks. Taking a few minutes to sit down or step away from the desk can reduce further fatigue and support the continuation of important activities for the person with MND.

Prioritise Important Events

Where possible, prioritise important or more complex tasks, such as work meetings or social outings, when energy levels are at their best. It can also be helpful to conserve energy in preparation for upcoming events such as a family dinner or theatre session, by spending a period of time resting beforehand.

Simplify Eating

Ordering delivered groceries online and buying pre-chopped or pre-made meals can reduce the effort required to prepare for meals. Eating more frequent, smaller meals throughout the day, and sitting down to prepare and eat food, are other effective ways to conserve energy.

Make Every Mouthful Count

Adding extra butter / oil / cream / full cream milk and sauces to meals can help increase the amount of energy and protein in each mouthful. Make sure this isn't altering a texture which may have been prescribed by the speech pathologist.



Optimising Sleep

Create a personalised space for rest with a calming scent or dim lighting. To promote optimal sleep, avoid screen time or the use of digital devices immediately before bedtime, keep heavy conversations separate from rest time, and try to keep a regular sleep routine. Try reducing caffeine and alcohol intake around sleep as well.

Use an Activity Diary

Recording significant drops in energy levels and noting the activities completed on that day and the previous day is important. It can highlight what has occurred and provide invaluable information for the healthcare team.

Advocating for Oneself and Their Boundaries:

Advocating for oneself and setting boundaries is important. If an appointment is scheduled for a time when the client is usually more fatigued and it's not suitable, it's perfectly acceptable to request a different time.

Modify Daily Activities

Sitting down when showering, dressing or preparing a meal can help conserve energy. Planning ahead by laying out clothes in preparation for the next day, or spreading lengthy tasks across several days, may also help with energy conservation.

Equipment to Assist With Fatigue

Equipment can be a valuable tool for individuals with MND, enabling them to continue engaging in activities they enjoy. A common misconception is that prescribed equipment must be used at all times, but this is not the case. For some, it can be utilised on days of increased fatigue or to conserve energy for important events. One common piece of equipment for managing fatigue is a powered wheelchair.

Here are some real-world examples of how using a powered wheelchair has allowed people to maintain their activities.



People living with MND were able to attend and participate in MND Victoria's Great MND Relay.



Using an electric wheel chair allowed a parent to attend their child's sporting events.



A keen footy supporter was able to attend the MCG and watch his favourite team.

Local Equipment Service

Depending on the location of the person with MND, equipment loans may be offered through their local MND organisation. For residents of Victoria, MND Victoria provides an equipment library with a wide range of options available through an allied health referral.

Other Equipment Items to Assist With Fatigue Management

Many options are available to help individuals with MND to conserve their energy.



Communication Aids

Voice amplifiers, text-to-speech apps, and tablets are just a few examples of the various communication aids available. These tools can simplify communication and help conserve energy. A speech pathologist and occupational therapist (OT) can assist in exploring and selecting the best options.



Over Toilet Frames

A toilet frame sits over a toilet and is height adjustable. Having arm rests on either side provides support and reduces the effort required to get on and off the toilet.



Modified Cutlery and Utensils

Lighter cups and cutlery, thicker handled cutlery (pictured), plate guards, and non-stick mats are options that can make eating easier, supporting good nutrition and effective fatigue management.



Mechanical / Electrical Beds

Electric or mechanical beds can assist someone living with MND to get in and out of bed, reducing the amount of energy required. Raising the bed head can help an individual reposition themselves as well as assist someone with respiratory concerns.



Sit to Stand Recliner Chair

Through the use of an electric function, this piece of equipment allows someone to easily stand from a seated position, reducing the amount of energy needed to rise. They also recline back, providing a comfortable position for someone to rest during the day.



Shower Chair

Showering may require someone to stand for a period of time, which can be tiresome. Sitting while showering conserves energy and may also reduce the risk of falls.

Over the toilet image sourced from Fisher Lane Mobility <https://fisherlane.com.au/>, Modified utensil Image sourced from Amazon <https://www.amazon.com.au> - Food Guard for Plates, Mechanical bed Image sourced from Fisher Lane Mobility <https://fisherlane.com.au/>

Non-Invasive Ventilation (NIV)

Non-invasive ventilation (NIV) is a medical treatment that helps individuals with respiratory problems breathe more easily without needing invasive procedures. It involves using a mask or nasal prongs connected to a ventilator, which assists with breathing by delivering air under pressure.

For someone with MND experiencing respiratory issues, NIV can reduce fatigue. It aids with respiration and reduces the effort required to breathe, thus alleviating fatigue associated with respiratory muscle weakness.

NIV can also improve sleep quality by ensuring adequate ventilation during rest, which is crucial for overall health and energy levels.

A respiratory physiotherapist specialises in managing respiratory conditions. It is advisable to consult a respiratory physiotherapist as soon as someone notices respiratory changes associated with MND.



The Importance of Checking in With the Healthcare Team Early

It is recommended to check in with an allied health team and General Practitioner as soon as someone feels ready. It's never too early!

The healthcare team may provide strategies early on, which can be used later down the track if and when they're needed. It's about providing tools for the toolbox that someone can refer back to when they are ready.

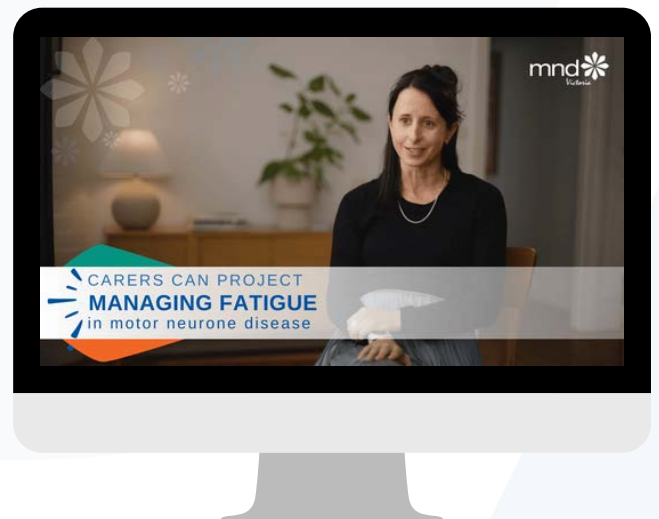
The health care team may suggest trying to implement some strategies early on before fatigue is really impacting someone's daily activities. This helps the individual get used to strategies before fatigue progresses.

Speaking with the GP is important as they may be able to prescribe medications to help with fatigue management. If the person with MND is experiencing mood changes, chatting with the GP can be a good first step in getting some mental health support.

Want to Learn More? *Check out Carers Can!*

The “Carers Can” project, 2024 created a suite of videos and booklets like this one. The videos feature health professionals, MND Victoria staff members, carers and people with MND. They provides helpful strategies, lived experiences and other useful tips.

www.mnd.org.au/carers-can



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- The “Carers Can” resources were created by



and

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FIGHT MND.

MND varies greatly between individuals. Always consult your healthcare team for a personalised plan.

This resource was developed in 2024 by MND Victoria using information provided by allied health professionals working within the MND health sector.

The information provided is not intended to replace the expert care provided by healthcare professionals.