



Managing Comfort in Bed

with motor neurone disease

This Booklet Covers:

- Reasons for Discomfort in Bed
- Early Strategies Which may Help
- Pillow Placement Demonstration
- Equipment Options to Explore With Health Team
- Importance of Seeking Support Early

Reasons for Discomfort in Bed for Someone With MND

Finding comfort in bed can be challenging for individuals with MND for various reasons, not all of which are directly related to MND. Identifying these reasons can help in finding an appropriate solution. Common reasons to consider include:

Weakness and Mobility

MND-related weakness can make it harder to change to a more comfortable position during the night.

Inadequate Bedding and Equipment

Inadequate bedding and equipment can contribute to discomfort. An old mattress, particularly one with a significant dip in the middle, can make movement to a comfortable position more difficult.

Pain

Pre-existing pain may affect comfort levels. An inability to easily change position in bed may also cause pain and can increase risk of pressure injuries (bedsores).

Communication Difficulties

Describing what is comfortable can be challenging for anyone, and this difficulty may be made worse if speech is affected by MND.

Fatigue and Irritability

Fatigue can make it harder to move and reposition during the night, impacting the ability to find a more comfortable position. It can also decrease someone's tolerance for remaining in an uncomfortable position.

Progressive Nature of MND

As MND progresses, solutions that previously improved comfort may no longer be effective. Consequently, comfort needs may change frequently.

Cognitive Changes

Preferences for comfort may change with those who experience cognitive changes.

What are Some Early Strategies Which may Help?

Discussing bed comfort needs with the healthcare team is essential. An occupational therapist (OT) and physiotherapist can assist in exploring available options. Some strategies to consider while waiting to see the healthcare team include:

Bedding and Pillow Adjustments

Some quilts or sheets can be heavy and difficult to move under for someone experiencing muscle weakness. Therefore a lighter option may be better. Simply changing the type of pillow to a more comfortable one - or adding in a second - may also improve comfort.



Setting up a Call Bell

If verbal communication is impacted, installing a call bell can make it easier for the person with MND to alert their carer of discomfort.

Temperature Regulation

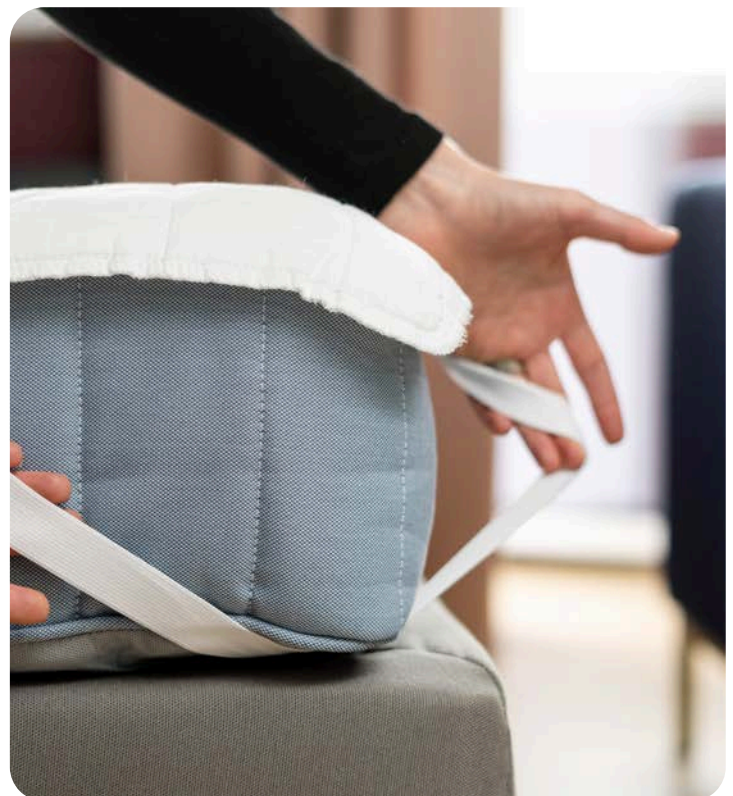
If nighttime movement is restricted, wearing warmer pyjamas may be essential to combat feelings of coldness.

Changing the Bedroom or its Configuration

If the bed is positioned against a wall or in an area that is difficult to access, rearranging some furniture, or sleeping on the other side of the bed, might be helpful. It may also be worth considering moving to another room in the house, if feasible.

Mattress Adjustments

Adjusting an existing mattress, such as by flipping or rotating it, may enhance comfort. Adding a mattress topper can also improve comfort. Alternatively, upgrading to a new mattress might be beneficial for better support and comfort, especially if the current mattress has been used for a long time. It can be helpful to consult with an OT before pursuing replacement beds or mattresses. An OT can provide guidance about the best options for improving comfort whilst maintaining or improving bed mobility. In some circumstances, it may be more appropriate to downsize from a double to a single bed, to pursue a bed with electric functions, or to use a specialised mattress.



Pillow Placement

Simply placing pillows in certain spots can significantly improve comfort. Here are two pillow positioning techniques. PLEASE NOTE: These positions may not be suitable for everyone living with MND. Always check with your healthcare team for a personalised plan.

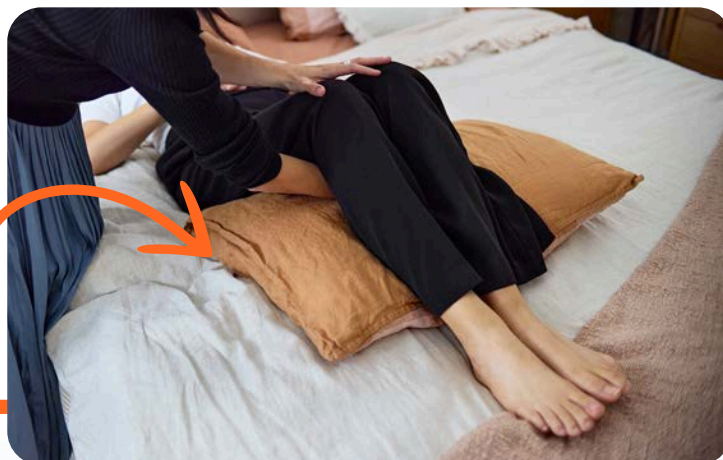
Option 1: Laying on back pillow placement

1

LAYING ON BACK, PLACE A
PILLOW (OR TWO) UNDER HEAD

2

CAREFULLY PLACE A PILLOW
UNDER THE KNEES.



Option 2: Side laying pillow placement

1

ROLL ONTO SIDE WITH HEAD RESTING
ON PILLOW. CROSS ARM CLOSEST TO
MATTRESS ACROSS BODY.

2

PLACE A PILLOW BEHIND THE
BACK TO PREVENT ROLLING BACK

4

CAREFULLY PLACE A PILLOW
BETWEEN THE ELBOW AND BODY



3

CAREFULLY PLACE A PILLOW
BETWEEN THE KNEES



HELPFUL TIP:

Taking photos once a comfortable pillow setup has been found is beneficial for sharing with OT, physiotherapists, and caregivers who are supporting the person with MND.

Equipment Options to Explore With Health Professionals

Consulting a Physiotherapist and OT early in an MND diagnosis is advisable. They can provide strategies and recommend aids and equipment options to support comfort in bed. While these options may not be needed immediately, becoming familiar with them early can help reduce additional stress when implementing them later in the diagnosis. Here are some available options:



Leg Lifters

A leg lifter is a device designed to assist individuals with limited strength in their legs. It typically consists of a strap with a handle that can be looped around the foot or lower leg. The person uses their upper body (torso and arms) to lift their leg into or out of the bed.



Bed Pole

This piece of equipment attaches to the bed frame and provides a handle to grab onto. This can be used to help with getting in and out of bed, as well as provide support when repositioning in bed.



Bed Cradle

The bed cradle is designed to keep bed linens off the lower limbs by creating clearance between the blanket and the person. The lower frame slides underneath the mattress to secure the cradle in place, while the upper frame is positioned horizontally over the lower limbs. Bedding is then placed over the frame, eliminating weight on limbs, making mobility easier.

Image sourced from Mobility and Wellness <https://www.mobilityandwellness.com.au/>



Bed Wedges

These wedges have numerous uses including being added to the bed to assist with body positioning and posture. They are often helpful for individuals with breathing difficulties. A bed wedge can be positioned under the head and neck to elevate. It can be placed behind someone's back, when they're lying on their side, to prevent rolling back.

Image sourced from Fisher Lane Mobility <https://fisherlane.com.au/>



Electric Bed / Mechanical Bed

An electric bed can enhance comfort for individuals with MND by allowing precise adjustments to the bed's position. It enables users to elevate the head, foot, or entire bed to find the most comfortable and supportive posture. This adjustability can help alleviate pressure, improve circulation, and ease breathing difficulties, making it easier for individuals to adapt their sleeping position as their needs change.

Image sourced from Fisher Lane Mobility <https://fisherlane.com.au/>

The Importance of Checking in With Healthcare Team Early

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

Speaking with the GP is important as they may be able to prescribe medications to help pre-existing pain and improve comfort in bed.

The health care 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 equipment early on to support comfort in bed. Depending on someone's location, equipment services may be available to rent or hire equipment items. MND Victoria has an equipment service which can provide equipment on request from the OT, for those in Victoria.

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



Acknowledgements

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- The "Carers Can" resources were created by



and **PROUDLY SUPPORTED BY 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.