



Taking Care of the Carer

in motor neurone disease

This Booklet Covers:

- The Vital Importance of Carers in MND
- The Reality of Caring for Someone with MND
- The Importance of Self-Care
- Practising Self-Care
- The Role of Grief in the Caregiving Journey
- Managing the Self-Care of Family Members
- When Should a Carer ask for Help?

The Vital Importance of Carers in Motor Neurone Disease

Motor neurone disease (MND) is a condition that gradually weakens muscles and affects movement, making everyday tasks increasingly difficult for the person living with the condition. Those closest to the person living with MND are essential in this journey, offering vital help with daily activities, providing emotional support, and improving the overall quality of life for those living with MND.

MND Victoria acknowledges that some people caring for their loved one prefer not to be called a carer. However, for the purpose of this booklet, the term 'carer' will be used to reference a family member or friend who has taken on the primary caring responsibilities.

The Reality of Caring for Someone with MND

Carers frequently find themselves in this role by circumstance rather than choice, without formal training, a handbook, or an onboarding process. It's natural for carers to experience a wide range of emotions which they may dismiss because, "they don't have the MND diagnosis themselves".

The reality, however, is that while they don't have the MND diagnosis, carers are still greatly impacted by MND. There is **one diagnosis but there are two journeys with it.**

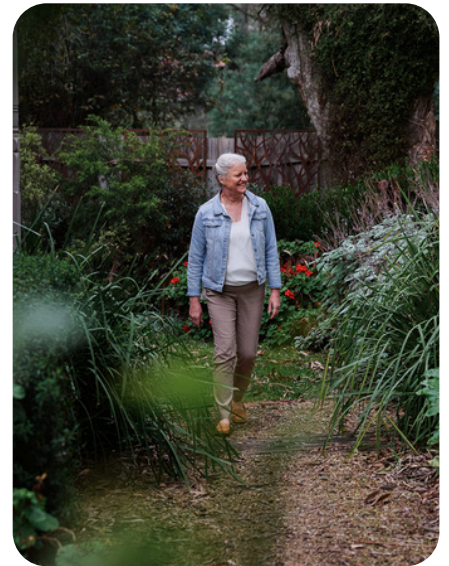
Therefore, it's essential for carers to focus on their own well-being, recognise their emotions, and practice self-care. Self-care can help to prevent caregiver burnout and ensures carers can continue supporting their loved one throughout their MND journey.

The Importance of Self-Care

Self-care is a way for someone to fill their own tank and recharge. **"You can't give what you don't have"**. When someone's energy reserves are depleted, everything can feel that bit harder.

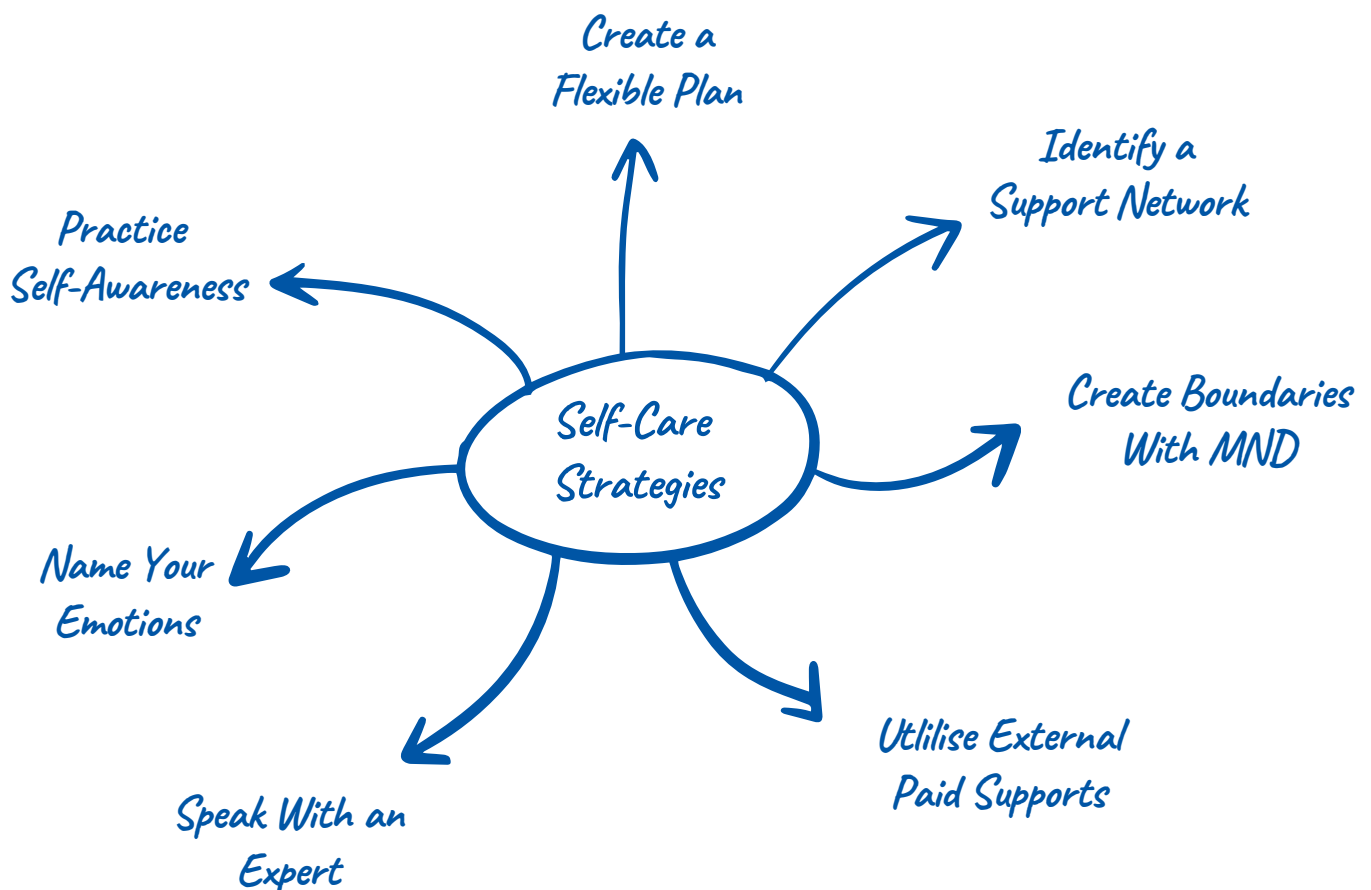
It's important for the carer to remember that self-care is a necessity, not an indulgence. It involves recognising what truly nurtures and sustains oneself. Everyone's self-care routine is unique, and what feels restorative today might be different tomorrow!

Remember - **taking care of yourself IS taking care of your loved one.**



Practising Self Care

Here are some basic strategies to kickstart a self-care routine. More detailed information on these strategies are provided later in the booklet.



1 | Practising Self-Awareness

Recognising signs is an important first step to self-care. Rising tension or irritability can indicate that energy levels are running low and a recharge is needed. These signs act like a car's dashboard warning light, signalling that something isn't functioning properly and needs attention before it leads to a bigger issue.

2 | Creating a Flexible Plan

Early on, it's great to create a flexible plan by first listing activities that recharge energy. This will be different for every carer. Book these activities in on a regular basis, to ensure time is set aside for self-care. A carer may find it helpful to refer to their self-care list when feeling overwhelmed. Here are some self-care examples:



Listen to your favourite music



Read a book



Mindful walk



Meditation



Garden



Get a massage



Book an exercise class



Do a puzzle



Coffee catch-up

3 | Identifying a Support Network

These are friends and family members who can be called upon in a pinch to provide a break and support. Writing out a list of things that people can help with, such as walking the dog, doing the grocery shop etc., is helpful as it can be provided to people when they ask, "How can I help?"

4 | Creating Boundaries

While MND can creep into many areas of someone's life, it is crucial to create some boundaries and have MND-free times. This may be a time of day, or day of the week, where MND discussions and appointments are avoided. This approach supports maintaining balance and preventing burnout.

5 | Utilising External Caring Services

Introducing external care services into the home can be challenging, especially for individuals with higher care needs. Relying solely on family or friends may not be sufficient, so external services provide the reassurance that complex needs are being managed. Engaging these services early, before they are urgently needed, helps both the carer and the person with MND to build rapport with the paid caregiver, making the transition smoother and less stressful down the line.

6 | Speaking With an Expert

Seeking professional support from a psychologist or counsellor can help carers manage the emotional and psychological strain of caring for a loved one with MND. Therapists can offer a safe space for carers to process their feelings and develop healthy ways to handle the stress of caregiving, in turn reducing burnout risk.

7 | Identifying and Naming These Emotions

A key component to self-care is the carers' ability to understand their own emotions. Being able to look at their emotions and understand why they're having them can really help to navigate them. A natural emotional response experienced by most carers is grief.

The Role of Grief in the Caregiving Journey

Grief is the many ways in which someone encounters significant loss and adjusts to it. Carer grief is a complex emotional process. It ebbs and flows over time as carers adjust to the gradual loss of their loved one's health and independence, and the life they once knew.

Grief in caregiving: it's individual, it's normal, and it's valid.

The anticipatory grief experienced by many carers can be exhausting and confusing at times but be assured, it is natural and common. It is important to honour all the experiences of grief because they signify what is important. We hurt where we care. Self-care involves recognising our unique experience and responding with care.



Supporting the Self-Care of Family Members

Caring for someone with MND may not be the only caregiving role someone has, and balancing this with family responsibilities can make it even harder to find time for self-care. However, preventing burnout is crucial for continuing to care effectively for both the person with MND and the family.

Applying self-care principles to family life can be beneficial. Just as with personal self-care, families should plan activities and times that focus on enjoyment and normalcy, separate from MND. Although MND will always be a part of life, creating space for fun, meaningful family moments can help recharge everyone.

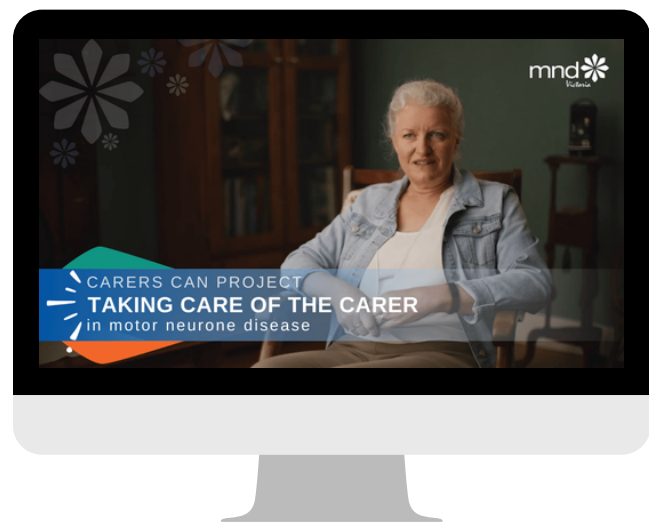
When should a carer ask for help?

The key takeaway is that it's never too early to seek help. A carer doesn't need to be on the verge of burnout to ask for support. In fact, reaching out early provides more tools and resources to use if needed. Consulting with a GP, psychologist, counsellor, or mental health professional as soon as possible is highly recommended.

Reach out to your local MND Association for information about supports available to you.

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 **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.