

10: Beyond the caring role

This section provides support if you no longer need to give the same level of care to a person with MND or your caring role has come to an end.

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: **www.mndassociation.org/MNDguides**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

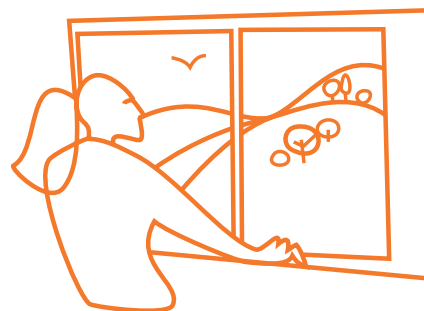
Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Caring and MND:
support for you**

10: Beyond the caring role



This section provides support if you no longer need to give the same level of care to a person with MND or your caring role has come to an end.

Please be aware that the following pages include sensitive information about end of life. Read this section when you feel ready to do so – you can always return to this later if wished.

Adjusting to life beyond the caring role can be difficult. Supporting someone with MND can be an intense time and it may feel very strange if you become less involved for any reason.

This may happen if the person with MND:

- accepts support services for personal care and becomes less reliant on you
- moves into a residential or nursing home
- is provided with NHS continuing healthcare where care needs are usually supported
- approaches end of life and receives additional care.

In all these situations, you can still take part, even if this means guiding the professionals who now provide care. This enables you to remain a member of the caring team and gives you time to adjust.

However, when the person dies, the caring role stops abruptly. Not only are you dealing with bereavement, but you can feel a sudden loss of purpose. You may have put the rest of your life on hold and feel as if you have no focus left. If you have lost touch with family or friends while caring, you may feel socially isolated too.

The emotional and physical challenges you face every day as a carer can catch up with you at this point.

“There was very little time for me to deal with my own emotions or concerns.”

While there was purpose and a sense of ‘get on and do’, you may have been surprised at how much you could achieve. Once the responsibility ceases, the toll on your body and emotional health may begin to show.

As you let go of the caring role, you can find your energy disappears. Emotions may still be challenging, but life itself can feel flat and deflated.

It is important to look after your own health and a check-up with your GP is recommended. Even if you feel you are coping well, it can still be valuable. You may have been under huge stress in the months or years before, but this pressure can often keep you going. Once you stop, you may find the tiredness overwhelming and become more aware of feeling ‘run down’.

Handing over care

Even if you wish to continue caring for the person with MND, there may come a time when external care is necessary. Accepting social care services at home may help for a while, but medical needs can become complex with MND. If this happens, it may

not be feasible to provide 24-hour medical care in the home, especially if you do not live with the person you support.

“She lives alone... I’m concerned that accidents will happen if I or someone else is not there.”

If you do live together and the person goes into hospital, a hospice or nursing care, separation may leave you feeling alone and defeated. This is a natural reaction, which may be accompanied by mixed emotions such as guilt, anxiety and relief. It can be a time of intense sadness.

See Section 7: Making sense of your feelings.

Yet, external care can help everyone to relax a little and spend time together without the constant pressure of the next task.

“It felt horrible, handing over to the hospice, but it soon became clear he was in the best place possible. The staff were incredible and he was treated like a human being.”

What if the person I support refuses to accept external care?

Even if you acknowledge external care is needed, the person with MND may refuse to accept this. In this case, unless an emergency admission happens, the burden on you is likely to increase. However, if round-the-clock care is required, this is simply not sustainable in the long term without support.

“My sole objective is to get through each particular day. With 24/7 responsibilities, sleep deprivation and continuous demands, you never have the time or energy to regroup, assess or even think straight.”

It is important to discuss your concerns, so the person with MND understands the challenges you face and the fears you may have about managing complex care.

If this is difficult to do or feels too emotional, ask for help from the local health and social team who support the person with MND. They can help by explaining to the person how external care:

- may be necessary for medical support
- may enable the person with MND to feel more comfortable
- can give you both more personal time to spend together
- still allows you to be involved in care tasks
- gives you time to rest as a carer to protect your health too
- can reassure the wider family, especially children and younger relatives
- can be guided by the wishes and preferences of the person with MND, through advance care planning.

The person with MND may feel as though control is being taken away, so advance care planning and advance decisions may be an important thing to consider. These can help someone feel that their ‘voice’ will be heard, even if they reach a point where they can no longer communicate or make decisions for themselves. Having their instructions recorded and registered with the appropriate professionals may help you to reach agreement on external support when needed.

See our publication *End of life: a guide for people with motor neurone disease for comprehensive guidance about planning ahead for future care.*

How do I stay involved?

Whether the person with MND is in hospital, a hospice or a nursing care home, you can still provide support if this is what you and the person with MND wish.

This can be achieved by:

- visiting the person to spend time with them and check they are being cared for in an appropriate way
- guiding medical staff and care workers about the person's needs from your own experience of their care
- helping the person to communicate if speech and communication have been affected by MND
- remaining involved in care tasks where possible.

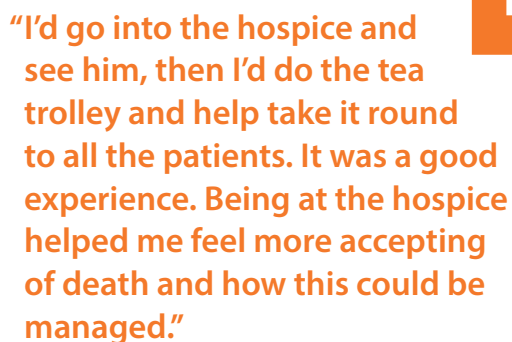
Assisting with care tasks may need to be discussed with the health and social care professionals involved. Find out what you can and cannot do in the circumstances, as health and safety may need to be considered. However, in most cases your help will be welcomed.

You may still wish to help with tasks such as:

- eating and drinking, including tube feeding if used
- hair washing and drying
- getting dressed
- other aspects of personal care
- assisted or passive exercise
- helping the person to write advance care plans or other important documents
- helping the person write to or email family and friends.

Ask the person with MND about their wishes – there may be lots of ways in which you can help, even if general care responsibilities rest with a professional team.

You may find that working closely with the professional care team helps if you feel anxious about the later stages of the disease and end of life. Nursing care in a hospital or hospice can be reassuring, as you learn more about how they provide support.



“I’d go into the hospice and see him, then I’d do the tea trolley and help take it round to all the patients. It was a good experience. Being at the hospice helped me feel more accepting of death and how this could be managed.”

Dealing with bereavement

You are likely to have been grieving from the point of diagnosis. This is known as ‘anticipatory grief’ and can cause intense sadness and anxiety. It can also lead to fear, which can be difficult to manage at times.

See Section 7: Making sense of your feelings.

In a sense, this can help prepare you, but you may be surprised at how hard grief hits when the person with MND dies. As their partner, relative or friend, you probably had a close relationship. In the caring role, you have shared their life on an incredibly intimate level. It can be hard to let go.

Although bereavement can bring a mix of difficult emotions, there can also be a sense of relief when the caring role ceases. This is a natural response after a particularly challenging time and not something to feel guilty about.

Relief does not show an absence of love, respect or deep loss. All of these can exist alongside each other. You may feel relief for various reasons:

- the demands stop and you can rest

- you no longer have to see the person you care about experience increasing loss
- your home becomes your own again, rather than focused constantly on MND
- the end of life stage is over and tension has been released
- you have seen the end and can now learn to deal with this, rather than anticipating and imagining what will happen
- you can grieve openly, without worrying about the possible effect of your emotions on the person with MND
- you have time to think about your own emotions.

Feeling relief does not mean other emotions disappear. You are likely to experience a range of feelings when grieving, from intense sadness to anger and guilt. These can come and go in waves and you may have periods where you feel numb or without feeling.

You may question yourself and wonder whether you could have done more or acted differently. Try to remember all the things you did do and take comfort that you did your best in difficult circumstances.

Supporting someone during difficult times can deepen your understanding of yourself and your abilities. This can encourage personal growth and help you to develop new skills and a different outlook.

“Growth does not necessarily mean that the person will be entirely free of the memories of what happened, the grief they experience or other forms of distress, but that they live their lives more meaningfully in the light of what happened.”

Professor Stephen Joseph,
University of Nottingham

Life will never be the same as before bereavement, but coming to terms with death does not mean that you have forgotten the person. It simply means allowing yourself to adjust, so that you can start to move forwards.

Bereavement support

There is a great deal to do when someone dies. This can provide purpose and routine in the immediate days and weeks following the death. While this keeps you occupied, it can be difficult in itself.

“Be aware of the effect the death may have on your health. The shock of suddenly not being a carer and having to deal with certificates, registration, stopping pensions before more payments are credited, notifying family and friends, fielding the inevitable telephone calls and arranging a funeral can be very stressful.”

It may also be the first time you have had to deal with the practical tasks needed at this point. This can feel complex and bewildering, especially when you are physically tired and emotions are high. Be prepared that organ or tissue donation may happen soon after death (this may have been pre-arranged according to the wishes of the person who died).

You may need to consider the following:

- registering the death
- letting others know about the death, including family, friends, work colleagues, and health and social care professionals who were involved in support
- informing organisations if benefits or financial support are being provided to the person with MND (the payments will need to cease)
- arranging the funeral

- claiming funeral and bereavement benefits, if you need and qualify for this support
- contacting the executor of the person's will or a solicitor for assistance with the person's estate.

You may find it helpful to seek information about what to do when someone dies, so that you have some guidance.

See our publication *End of life: a guide for people with motor neurone disease*, which offers a range of information about putting affairs in order and what to do when someone dies.

Strong emotions are to be expected when grieving. It may take time for these feelings to become manageable and for you to feel in control again. Even then, grief can reappear at unexpected moments. Something may trigger sadness or a mix of difficult emotions.

However, if these are persistent and you feel continuously low, do seek advice from your GP. You may be referred for counselling or directed to an organisation that specialises in bereavement support. There may be a waiting list if these services are stretched, but it can be comforting to know you're on a list and support is being arranged. These services can be very helpful.

See **Information sheet 14B: Bereavement support** for detailed guidance.

Adjusting to life beyond the caring role

After the demands of caring, your world can suddenly feel very empty when this stops. The endless calls, appointments, home visits, assessors and ever changing routines with MND are gone. The health and social care professionals who were part of your life are no longer in contact.

"No one comes here anymore. The house is empty."

Loaned equipment is collected or you may need to arrange for purchased equipment to be sold or taken away. This can help if you find it hard to be reminded of difficult times, but may be distressing if you want to retain a connection to certain memories.

"The equipment was taken away the day she died. I wish I could have held onto the riser recliner chair a little longer. My wife spent so much time in that chair."

MND needs increasing levels of care and can take over your time almost completely by the end. Adapting to life without this constant demand may sound like an easy thing to do – certainly easier than caring. However, you may experience a loss of purpose that can hit hard, especially when dealing with grief.

If possible, it can help to think ahead, so that you have plans in place to help you adjust. If you can identify difficulties you might face, it can help you work towards the life you would like to have, despite the grief and loss you are likely to feel.

When doing this, allow space to rest and just be. Don't expect too much of yourself, too soon. You need to:

- look to your own immediate wellbeing and take advice from your GP
- give your emotions and body time to heal from the stresses of the caring role
- give yourself permission to think about life on your own terms again, without feeling guilty.

Above all, give yourself credit for all that you did to enhance quality of life for the person you supported. Now it is your turn to think about your own quality of life and what happens next.

When you feel ready to take the next step, do what feels right for you at the time. There is no one right approach.

Rebuilding relationships

You may feel angry towards family and friends who appear to have 'abandoned' you during your caring role. Yet, there may be reasons they were unable to provide support or found this difficult to do. It may be worth contacting them to see if you wish to rebuild the relationship, which may provide a much needed connection at this time.

Those who have been in close contact and did provide support may also need time to adjust to a changed relationship with you. The way you interact now will be different to the way you worked together during the caring role. It can help to be prepared for this and acknowledge the changes. Talk to those close to you, so that everyone has a chance to discuss how they feel.

Hobbies and interests

In time, you may be able to consider revisiting hobbies, social activities and projects that have been on hold during the caring role. Think about things that interested you before and whether these still have the same appeal. You may prefer to take up something new, but either way, joining a club, group or evening class may help to open up your social circle again and bring opportunities.

You may have shared certain activities with the person you supported. These may feel difficult or upsetting to do without them, so don't worry if you need to avoid these for a while. These feelings may lessen over time, in which case try these activities again, when you feel ready. However, it may free you up to choose new interests, perhaps something you have always wanted to try.

Returning to work

You may have left work during your caring role to manage the increasing demands. This can interrupt a career and you may feel a loss of confidence about returning to the workplace.

If you do want to find work again, think about the skills and abilities you have learnt as a carer:

- coping under extreme pressure
- dealing with complex care arrangements and services
- acting as an advocate, supporter and administrator for the person with MND.

These are transferable skills for many areas of employment and could help you return to your previous career or start something new. Many employers understand why carers need to take a career break, so it may not be as much of a barrier as you think, but be persistent. It may take a while for your confidence to build.

Arrange appointments with your local careers advisory service and employment agencies to explore possible avenues of work.

If you do return to work, it may feel strange at first, so expect a period of adjustment.



“Work seems a very cut-throat place compared to the world of caring, which I enjoyed very much and found very rewarding.”

If it does feel difficult, think about the value it may bring, with:

- a new sense of purpose
- routines that bring structure to your day
- work skills and confidence
- social contact with colleagues
- improved income.

Ensure you give yourself time to relax outside of work during the first few months. This will help you adjust to the new routines.

Key points

- If you feel external or nursing care may be necessary for the person you support, but find this difficult to discuss with them, ask a health and social care professional to guide this conversation.
- If the person you support accepts a place in a nursing home or hospice, you can still be involved in their care if this is your wish.
- When the person you support is in a nursing home or hospice, you may find it gives you both more personal time to spend together as the care demands reduce.
- Following the death of the person you support, difficult emotions are to be expected. These tend to come and go, but if they persist and you feel very low after several months, ask your GP for advice. They may refer you to specialist help.
- Allow relationships with wider family and friends time to rebuild during bereavement. Everything can feel different after someone dies and you may all need time to adjust.
- The caring role is a difficult and demanding role. Recognise all the support you provided and be proud of all you achieved.

Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

From our information sheet range:

10D: NHS continuing healthcare

14B: Bereavement support

From our other publications:

Living with motor neurone disease: a guide about MND to help manage the impact from diagnosis onwards and maintain the best possible quality of life.

End of life: a guide for people with motor neurone disease: a candid and comprehensive guide about planning ahead for the later stages of MND and wishes for future care.

How to access publications and further information:

Most of our publications can be downloaded at: **www.mndassociation.org/publications** or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and your regional care development adviser (RCDA).

See Section 11: *How the MND Association can help you for details about our services.*

Online forum:

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<http://forum.mndassociation.org>

Information for professionals

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

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For references and acknowledgements please refer to the full guide, *Caring and MND: support for you*.

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www.england.nhs.uk/tis