mnda
motor neurone disease
association

1: New to caring?

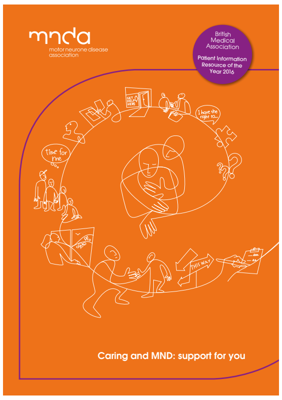
This section looks at what it means to take on a caring role and some of the things you need to think about.

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/carerguide**

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

1: New to caring?

This section looks at what it means to take on a caring role and some of the things you may need to think about.

> "In my case, I had no idea what being a carer was and what it involved."

If your partner, relative or friend has been diagnosed with MND, there will be many changes ahead. These changes affect not only the person with the disease, but those close to them. If you find yourself in a caring role, it can be very challenging, but there is support available.

Over time, a person with MND will need increasing levels of care. If you are the main carer, you may have to put aside other things that feel important and it can be difficult to maintain a sense of 'you'.

Supporting someone with MND is not easy, but this guide is here to help you think about your own needs. This is important for your own wellbeing. If you wish to continue in the caring role, your wellbeing is also important to help you manage the challenges ahead.

Do I need to call myself a carer?

Calling yourself a carer may feel uncomfortable at first. You may see yourself as a son, daughter, husband, wife, partner, relative or friend, and the support you give as simply a natural part of that relationship.

> "I love him, so I care for him."

However, the word carer is used by health and social care services to describe those who provide support to others. Accepting and using this term can help you identify and access those services.

There are various types of carer and we will use these terms in this guide:

Carer: this usually describes an adult carer, typically a partner, relative or friend of the person needing support, who is not paid for the care they provide. We have written this guide for you.

Young carer: also an unpaid carer, but someone 18 years of age or younger who assists with some care tasks or may even be the main carer.

See Section 9: *Support for children and young people* to find out more about how to help young people affected by MND.

Care worker: a paid carer, provided by social services, an agency or in a care home, as part of a care package. Or employed as a personal assistant at home by the person needing support.

Health and social care professional: someone involved in either the clinical care or the social care of a person who is unwell. They may also provide personal care in hospital, a hospice or a nursing care home. You are likely to meet a wide range of these professionals and we will describe various roles throughout the guide.

See Section 5: *What kind of support is available?* for more details about care workers, and health and social care professionals.

What does being a carer really mean?

Although there are many common experiences between carers, your situation will be affected by personal circumstances.

Carers can be:

- any age, gender, race or social background
- retired, unemployed, employed, self-employed or in education
- at school if they are a young carer
- a family member, friend or neighbour
- living with the person with MND
- not living in the same household, but in regular contact.

More than one person may start to help with care and household tasks, but in most cases a particular individual takes on the responsibility of becoming the main carer.

Your needs and emotional responses may be very different to those of another carer. MND can place great strain on the entire family and friends too. When someone is diagnosed, it can come as a huge shock. Everyone involved will need time to adjust.

See Section 7: *Making sense of your feelings* and Section 8: *Looking after yourself*.

> **"All the tasks I had to take on and learn to do were not by choice, but having to."**

Some tasks may not feel like support, as you would do them anyway as part of your daily routine. Over time, you may need to do more. You are likely to take on activities that are new to you. The person you support may no longer be able to do certain things for the household or for themselves. Roles tend to change and this can affect relationships.

As MND is a disease that will progress and get worse, the person's care needs will increase.

> **"I really began to worry about how I was going to cope; I am no nurse and the last thing I wanted to do was look after anyone."**

If you take on a caring role, there are many ways to provide support. Every individual with MND will have varied needs and every carer will face different situations. You may have developed skills as a carer previously or you may have no experience.

> **"When I care for my wife, I know she is happy and comfortable…it's hard work but rewarding."**

You may find it rewarding or you may find it extremely stressful, or both. No particular viewpoint is right or wrong.

You need to find your own path and try to ensure help is in place before it is needed. Planning ahead is of the utmost importance. Making arrangements for equipment, care support or services can take time, so be prepared where possible. If you wait until the need becomes urgent, help may not be instantly available.

See Section 4: *Carer's assessment* for more details about how to get your needs assessed.

See Section 6: *Work and financial support* for more details about flexible working and benefits.

See Section 5: *What kind of support is available?* for more details about support options.

Do I have a choice?

You may accept the caring role without question, but for some this is a difficult choice. For example, you may be concerned if:

- you are in poor health yourself and feel unable to meet the level of support needed
- you have other people depending on you and feel overwhelmed
- your relationship with the person needing support is difficult and the challenges ahead may make this harder
- you feel uncomfortable about providing intimate personal care, perhaps because of the type of relationship you have (for example, a son or daughter may not wish to provide personal care to a parent or you may simply wish to preserve your existing relationship with your partner)
- you or the person with MND feel unsure about you handling their finances
- you need to take time out from work (if the person's care needs increase) and this causes financial hardship.

Your concerns may grow over time, but you do have choices. For example, you may be able to get support for some tasks. This can help if the demands become overwhelming or if personal care feels uncomfortable. If the person's care needs become complex, you may need increased support from care workers and the health and social care team.

If you are unable to provide support or the care needs become too much for you to manage at home, you and the person with MND may need to consider other options. This could mean residential or nursing care, or there may be others within your immediate circle who can offer help.

Whatever the circumstances, you do have a choice on the amount and type of care you provide. However, additional support is not always easy to arrange. You and the person with MND will need to be assessed to find out the level of support you require.

You are not alone

Being a carer can often lead to a sense of isolation. The person with MND may find it harder to leave their home if they become less mobile. They may have problems with speech and communication and you may even notice changes to their thinking and behaviour.

Conversation and expression of emotion may become more difficult. If you were close, you may feel that you are losing parts of the relationship that meant a great deal.

See Section 2: *What to expect* for more details about the effects of the disease.

Social contacts can decrease too. You may find you have less time for work, leisure, friends and family. Others may not realise the pressures you face or find it difficult to know how to help. This can leave you feeling that nobody understands what you are going through.

> **"I feel emotionally isolated. Everyone expects me to be 'wonderful' and I try to put on a brave face."**

However, not only do services exist to support carers, but other carers can provide peer support. They are facing similar challenges and can share experiences, tips and ways to get through the lows.

Everyone's situation is different, but it is important to recognise there are people you can talk to who understand. Even if this does not feel right at the moment, it can help to know you are not alone and where to go for help in the future.

Here are various contacts you may find useful:

- our MND Connect helpline can direct you to our services (as shown in this list) and external services. The team can also provide a listening ear if you just need to talk. Telephone: **0808 802 6262** or email: **mndconnect@mndassociation.org**
- we provide local support through our branches and groups, where you can meet other carers who support someone with MND
- our volunteer Association visitors can provide support by phone, email or face-to-face
- we have regional staff who can help influence local health and social care services in complex situations.
- we host an online forum, for people with or affected by MND to share experiences in a safe environment, at: **https://forum.mndassociation.org**

Local carer centres, groups, organisations and charities offer support for carers. You can find out about services in your area from your local authority, or in Northern Ireland, from your local health and social care trust.

See Section 12: *Useful organisations*.

Keeping track

It can be helpful to keep a log of the care tasks you do for a short period of time, perhaps across a week or two. This may feel difficult if you are under pressure, but it can help show the level of care you provide. If you repeat this a few weeks later, it can also show if the level of care is increasing. This can help you access suitable support at a carer's assessment for yourself or at a needs assessment for the person with MND.

It can also help other health and social care professionals. For example, an occupational therapist can assess needs within the home and help arrange or advise on assistive equipment and aids. If you provide details about changes to daily routines, they will have a clearer picture to work with. You may also find this useful when claiming certain benefits, where evidence of the caring role or of the person's disability may be required.

> "The list of everyday jobs became more and more."

In response to your feedback, we have provided a *Care summary* at the back of this guide to help you keep notes. It enables you to:

- identify the types of task you do (some tasks are already listed and you can add more)
- note down the level of care and time each task takes
- track any increase in care over time.

At first, you may only need to give limited support. However, if the person you support cannot do tasks listed on the *Care summary* without your help, then you are probably taking on the role of carer.

You can write directly on the *Care summary* or photocopy it to keep as a master. You can also download and print spare copies by selecting *Our guides and packs* at: **www.mndassociation.org/publications**

Key points

- Recognise you are a carer, but try to maintain a life away from the caring role and, where possible, retain aspects of your existing relationship with the person you support.
- Don't be afraid to ask for support from others (relatives, friends or care services).
- There is no 'right' way of being a carer.
- Let your GP know you are a carer. Many GP practices provide health checks and support for carers, and can help arrange appointments at suitable times.
- Contact your local adult social care services and ask for a carer's assessment.

- Contact your local carer's centre or group and ask about services and group meetings in your area. Talking to other carers can often be a great support.
- If you work, tell your employer you are a carer if you feel comfortable to do so. They may be able to help with flexibility at work.
- Avoid hasty purchases for equipment or aids. MND can change quickly and an expensive item may not be useable by the time it arrives. Get an independent assessment from an occupational therapist, who can assess current and future needs. They may also be able to provide some items free of charge.

See Section 11: *How the MND Association can help you* for details about our MND support grants and equipment loans.

- Make use of your strengths, but don't be afraid to ask health or social care professionals for advice or training if needed.
- You will encounter problems, but trial and error leads to learning and finding the best way through. Again, don't be afraid to ask for help.
- Try not to place unrealistic demands on yourself. Do essential tasks first and let other things wait. Reserve time for both yourself and the person you support to do things you really want to do.

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:

1B: Health information in other languages or formats

3A: MND care centres and networks

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.

What you should expect from your care: a pocket guide based on the NICE guideline to help get the most out of health and social care appointments.

Telling people about MND: how to communicate about the disease with family, children, friends and professionals.

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 regional staff.

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:
https://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.*

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

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**

This resource has been evidenced, user tested and reviewed by experts.

Trusted
Information
Creator

Patient Information Forum