



Caring and MND: support for you

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

What do professionals say about this guide?

“You’ve done a fabulous job of simplifying very comprehensive (sometimes confusing) legislation – well done. I would like to share the information with my providers, as I think it is an excellent template to help carers, whoever they are caring for. Excellent, well-written and easy to understand.”

Sonja Woodhouse, Commissioning Manager Carers Lead, Northamptonshire County Council

“As ever with the MND Association, the information looks very clear and is pitched at a good, supportive level for families.”

Amanda Mobley, Clinical Psychologist, Community Neuro-Rehabilitation, Walsall Healthcare NHS Trust

“This guide is fantastic. It may be long, but it’s packed with essential info and you can read at your own pace.”

Pauline Callagher, MND Care Centre Co-ordinator, Preston Care Centre, Royal Preston Hospital

What do carers for people with MND say about this guide?

“This information is so useful. I think that sometimes people take on a caring role, but don’t realise they are carers and don’t get the help that is available to them.”

“I didn’t realise how much of a carer I was until afterwards. Having this sort of information at hand would have really made a difference. I didn’t realise the help available to me as a carer.”

“I particularly like the write-on forms at the back and wish these had been available when my husband and I started on the MND path.”

Foreword

I'm Charlotte Hawkins and I am a Patron of the MND Association. I'm also better known, depending on your point of view, as a TV presenter, a wife and a mother.

My Dad died from MND in January 2015, so, if this is the first time you are reading *Caring and MND: support for you*, I have some understanding of what you are going through.



For my family, our lives changed completely when Dad began to lose his balance. He knew something was wrong, and he knew it wasn't good. It took six months to get a final diagnosis in 2011 and it shook our world. We didn't know much about MND and were shocked to find there is no cure.

Remaining positive to the end, Dad bore his disease with great dignity. It is a difficult diagnosis to come to terms with – not just because it is life-shortening, but because you become completely reliant on those caring for you.

Motor neurone disease takes its toll on all family members, but especially those who provide support. Dad needed help doing everything, from being fed and washed, to moving around. Care workers came twice a day to help him in and out of bed, but my Mum was with him constantly and looked after his every other need. This can make it very difficult to look after yourself as the carer, with little time or energy to think about your own needs.

Like my mum, you may not even see yourself as a 'carer', but as a partner, relative or friend. Accepting the title of carer however, helps open doors to a range of support services. These can be invaluable at such a challenging time – particularly if the person with MND has problems with mobility or communication, and your world seems to get smaller. This can feel isolating for you both.

Caring for someone with MND creates huge emotional and physical demands, and may

impact on your health, finances and sense of identity. Yet it's vital to think about your wellbeing, both for yourself and to stay strong for the person you support.

There is help at hand here. This guide can't answer every problem, but suggests ways to access support when needed. There may be times when day-to-day life seems overwhelming, so make the most of the help available. Don't feel guilty about asking for this or think that you should go it alone – we all need support through difficult times.

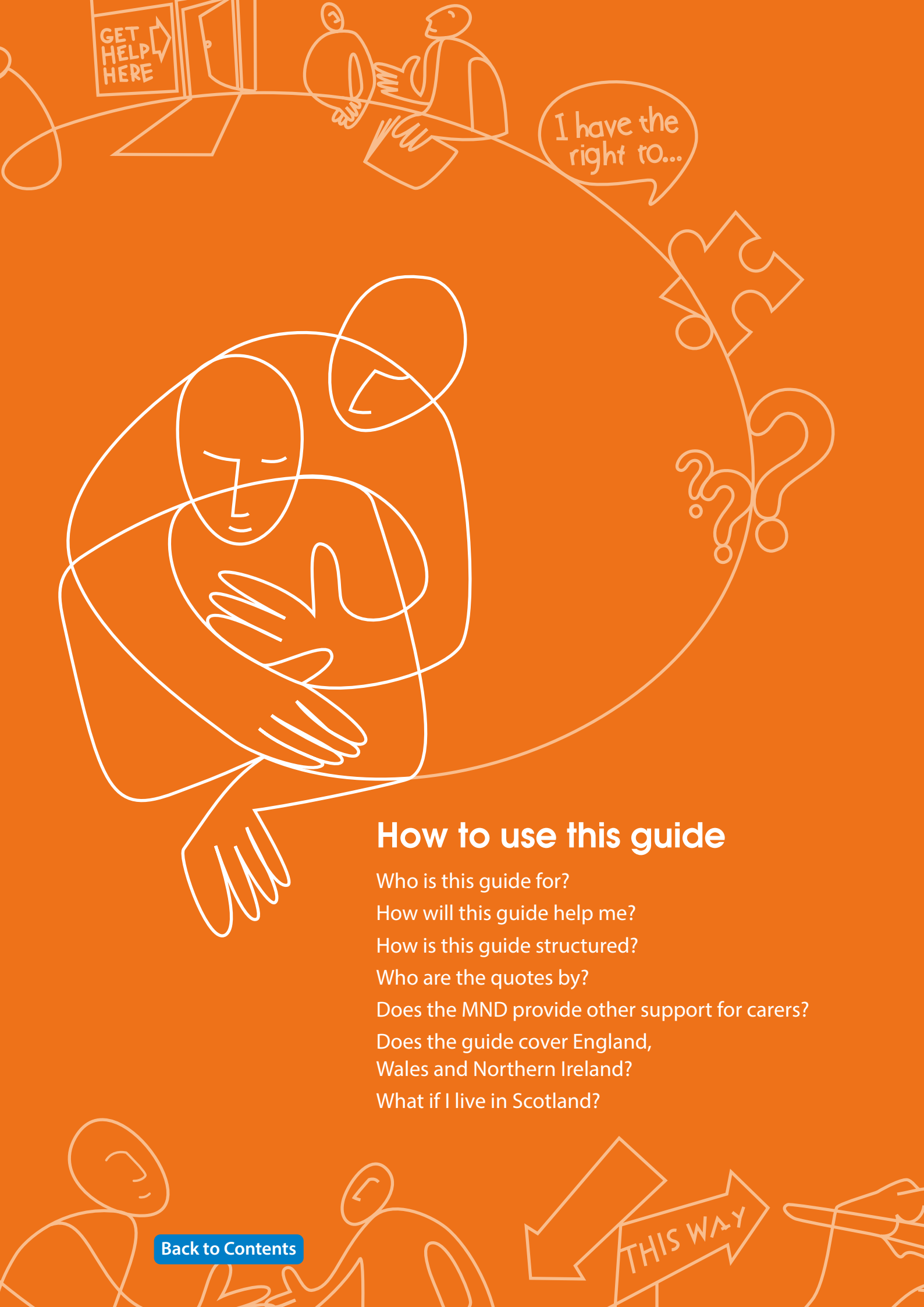
With the right help, you can try to focus on positive aspects of caring – spending time with the person you are supporting and doing things you both want to do, rather than just daily necessities.

There is a wealth of guidance in the following pages. Read at your own pace and dip in when you need to. Hopefully this guide will help you see that you matter too. You are on a difficult journey, but it may feel a bit easier with support. I wish you all the best for the times ahead, sending you love, and please don't forget, you are not alone.

A handwritten signature in black ink that reads 'Charlotte Hawkins'.

Charlotte Hawkins

Patron of the MND Association



GET HELP
HERE

I have the
right to...

How to use this guide

Who is this guide for?

How will this guide help me?

How is this guide structured?

Who are the quotes by?

Does the MND provide other support for carers?

Does the guide cover England,
Wales and Northern Ireland?

What if I live in Scotland?

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THIS WAY

How to use this guide

Supporting someone with motor neurone disease (MND) is physically and emotionally demanding. This guide explores the challenges you may face and ways to consider your own needs and wellbeing.

Who is this guide for?

If you support a partner, relative or friend with MND, then you are in a caring role. This guide is aimed at family or unpaid carers who are 18 or over.

If children and young people are helping to support in any way, we provide a section to help you consider their needs.

See Section 9: Support for children and young people.

We also provide a wide range of information for people living with MND.

See Further information at the end of each section for details about ordering our publications.

The demands of MND can impact heavily on carers. We have referenced the symptoms and effects of MND where relevant, but our primary aim is to keep your needs in mind.

How will this guide help me?

This guide does not claim to hold all the answers and we recognise the way ahead will be challenging for you. However, you are not alone. Our aim is to help you think about your own needs, which can be very difficult when meeting the demands of MND.

When you find yourself in a caring role, it is easy to put your needs after those of the person you support. However, if you ignore your own wellbeing, you may place your health at risk. This could mean being unable to provide support for a short or long period of time.

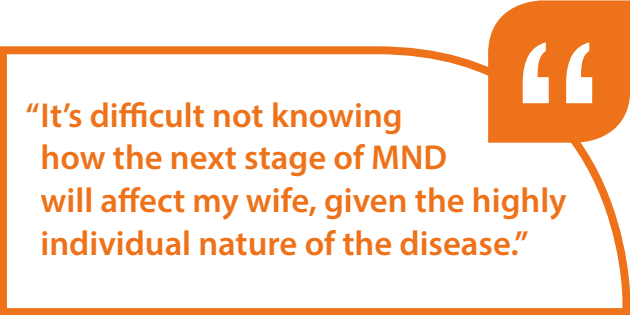
“I’d like a guide similar to the one available for people living with MND, but aimed at the carer, with emphasis on what to expect as the disease progresses.”

Caring and MND: support for you can help you:

- explore how the title of ‘carer’ can help you access support, even if you prefer to be seen as a partner, relative or friend
- adjust to the caring role, if this is what you wish
- prepare for the challenges that lie ahead
- identify support for the person with MND if you are unable to help for a while or do not wish to be a carer
- determine your rights as a carer and gain access to the assessments and benefits you may be entitled to claim
- identify the types of service and support that may be available for you as a carer
- make sense of your feelings
- look after your own health and wellbeing
- explore how palliative care can help you and the person you support achieve the best possible quality of life
- think about how to look after yourself if the caring role changes or stops.

You may prefer to tackle the information in small steps, as and when it feels right to do so. You can refer back to this guide at any time.

Not all of the content will necessarily apply to you and certainly not all at once. Everyone supporting a person with MND will share similar situations, but your experience will be unique.



“It’s difficult not knowing how the next stage of MND will affect my wife, given the highly individual nature of the disease.”

How is this guide structured?

This guide is divided into four main parts, with clear sections to help you to find the subject matter you need easily:

Part 1: Practical support

The first part looks at the activity of the caring role, from routine tasks to accessing external services.

Part 2: Emotional and personal support

The second part explores the varied reactions you may experience and how to manage these. Mixed feelings are normal, expected and shared by most carers at some point during the pathway of care.

Part 3: Further help

The third part provides further information about services, publications and useful organisations. It also contains our write-on pages to help you prepare.

Part 4: Keeping notes

The fourth part provides write-on pages to help you keep important information and prepare for the way ahead.

The contents page and the index will help you to locate specific subject matter, under clear headings. If you are using the online version, you can click on the contents and index entries to go to the exact page you need.

You will also see certain elements emphasised, such as quotes and key points.

Who are the quotes by?

All quotes featured in this guide are from carers like yourself, who have been supporting someone with MND. We have included them to share experiences.

Does the MND Association provide other support for carers?

Whether or not you live with the person with MND, this guide will help you to access a range of support from ourselves at the MND Association, health and social care services and other useful organisations.

See Section 11: *How the MND Association can help you.*

Awareness of available support is important, not only to help the person with MND, but to look after your own health and wellbeing.

As a first step, you may wish to contact our helpline team, MND Connect. They can answer questions, listen and direct you to our services, including our Association visitors, regional staff, branches and groups. They can also provide contact details for appropriate external services.

MND Connect

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Association, 6 Summerhouse Road,
Moulton Park, Northampton NN3 6BJ

Website: **www.mndassociation.org**

Does the guide cover England, Wales and Northern Ireland?

Yes, the MND Association supports everybody living with or affected by MND in England, Wales and Northern Ireland.

Where appropriate, we have clearly stated any differences between the health and social care systems in these countries. However, due to ongoing reforms, always check details with your local providers when accessing support.

See Section 12: *Useful organisations*, for ideas on where to seek support in England, Wales and Northern Ireland.

What if I live in Scotland?

If you live in Scotland, please contact MND Scotland for advice on specific support and services.

See Section 12: *Useful organisations* for contact details.



Part 1: Practical support

Section 1: New to caring?

Section 2: What to expect

Section 3: Your rights as a carer

Section 4: Carer's assessment

Section 5: What kind of support is available?

Section 6: Work and financial support



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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.

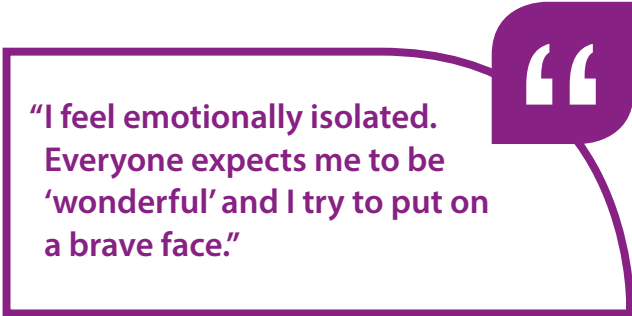
You are not alone

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>

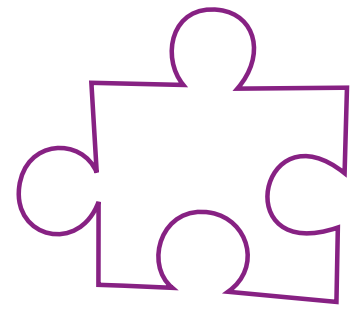
Information for professionals

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

www.mndassociation.org/professionals

2: What to expect

This section provides an overview of MND and the care that may be required.



Everyone's experience with MND is different, whether living with the disease or providing support. As this guide is about your needs and wellbeing, this section does not tell you how to provide care. The aim is to help you prepare for the challenges you may face, with guidance about where to get support when needed.

When ready, you may wish to read more detail about managing symptoms and care. We guide you to relevant publications in this section.

See *Further information* at the end of this section for a summary list of all relevant publications and how to order these.

"I have no knowledge of needs that may arise for him or what support is available."

Various health and social care professionals are mentioned in this content. You can find out more about their roles later in this guide.

See *Section 5: What kind of support is available?*

"You have to think ahead and anticipate future needs and support requirements. Forward planning is essential because there will always be a delay while necessary support is being arranged."

What is MND?

Nerves in the brain and spinal cord control how muscles work. These nerves are called motor neurones.

With MND, motor neurones gradually stop telling muscles how to move. When muscles no longer move, they become weak, which leads to stiffness and loss of muscle mass (known as muscle wasting).

MND is a life-shortening illness that can affect how someone walks, talks, eats, drinks, breathes and in some cases, how they think and behave.

"Although I knew MND was life-shortening, I knew nothing about the symptoms or the fact that it is unpredictable, and can progress so quickly."

MND is not a common disease. It usually affects adults more than 50 years of age, but younger adults are diagnosed.

There is currently no cure for MND, but a range of health and social care professionals can help manage symptoms to ensure the person has the best possible quality of life.

These professionals can also support you as the carer and should consider you as part of their team. You will become an expert in the care of the person you support and your knowledge is important to the professionals involved.

See our guide, *Living with motor neurone disease* for more detail about the types of MND.

Is Kennedy's disease a type of MND?

Kennedy's disease is a different and rare disorder of the motor neurones. Like MND, it leads to weakness. People with Kennedy's disease often have a normal life span as the condition progresses slowly.

As Kennedy's disease has similar symptoms, it can be confused with MND during diagnosis. However, it is caused by a clear genetic mutation that can be found through gene testing. Normally, Kennedy's disease only affects men, but women carry the genetic mutation. There is some evidence that women can occasionally develop the symptoms, but this is rare.

The MND Association also provides support for people with Kennedy's disease, their families and carers. If you support someone with Kennedy's disease, you may also find this guide helpful.

See information sheet 2B: *Kennedy's disease* for more detail about this condition.

What causes MND?

It is still not possible to be clear about what causes MND, as each person may be affected by different triggers (triggers are things that might cause a disease to start).

"He researched other conditions before he was diagnosed with MND, but I think he was exploring possibilities on his own."

MND usually occurs with no apparent family history of the disease. In these cases, a mix of genetic and environmental triggers is thought to be involved, although genes may play a smaller role.

Environmental triggers could be things that you eat, drink, touch or breathe, or a mix of these. As the triggers can be different for each individual, there is no simple way to find out why someone gets the disease.

Research into the disease and its causes is progressing, including projects funded by the MND Association. As a result, our understanding of how motor neurones work is constantly advancing.

What if there is a family history of MND?

In a small number of MND cases, a mistake in the genetic code is inherited. Other triggers are still thought to be necessary for the disease to actually begin.

See our research information sheets on inherited motor neurone disease.

If you are concerned about the possibility of a family history of MND and what that could mean for those close to you (in terms of inheriting the genetic code), you may wish to seek genetic counselling. This is not a form of psychotherapy, but a genetic counsellor can explain the facts and provide accurate information about the implications for your family.

This includes information about options such as genetic testing, but testing is only available for some of the genes that play a part in inherited MND. Results are not necessarily conclusive.

Choosing to be tested can be a very difficult decision for someone to make, as it affects the wider family. We would advise genetic counselling from a neurological expert experienced in MND. In the first instance, ask the neurologist involved in the diagnosis or care of the person with MND.

What are the likely symptoms of MND?

“I have no idea if what’s happening to my partner is normal.”

Muscles in the hands, feet or mouth are usually affected first, but not necessarily all at once.

MND can cause:

- weakness and increasing loss of movement in limbs
- twitching and rippling sensations under the skin
- muscle tightness and cramping (which may cause pain)
- problems with breathing and tiredness
- difficulties with speech, swallowing and saliva
- changes to thinking and behaviour.

Someone may also have unexpected emotional reactions, where they cry when happy, or laugh when sad. This is called emotional lability and can feel distressing, but their health and social care team can provide support. This symptom does not happen to everyone with MND.

See later heading: *Emotional support and emotional lability.*

MND does not usually affect:

The senses: sight, hearing, smell, touch and taste. However, tightening of muscles and lack of movement can cause pain. Exercise and assisted exercise can help.

The bladder and bowel: however mobility problems can make it more difficult to get to the toilet and reduced mobility may also cause constipation (as movement helps the bowel to work).

Primary lateral sclerosis, a type of MND, may cause some people to feel an urgent need to urinate, even when their bladder is empty. The GP or neurologist can advise about medication to help control this symptom.

Sexual function: while function is unaffected by MND, sexual expression may be more difficult due to feeling tired, loss of movement and the emotional impact of dealing with the disease.

See our booklet on *Sex and relationships.*

“I feel it should be stressed that no two people with MND have the same needs and, as time goes on, care becomes more difficult.”

Symptom control can range from exercise and therapy, to treatment and medication. However, the person you support may have other symptoms not mentioned here or other conditions not connected to MND, such as viruses, illness or injury. Always consult a GP or the wider health and social care team if you have any concerns.

See our main guide: *Living with motor neurone disease and information sheets for symptom control and suggestions on daily living.*

How will I be involved?

This may be the first time you have supported someone as a carer. With MND, support needs can be complex and present unusual problems.

“I wasn’t qualified to care, had no training and feel that carers are not understood. At first, I could only bring limited ability to the role.”

Ask the GP or another member of the health and social care team for advice when symptoms first appear. This can help you and the person with MND to feel more informed and access help in a timely way. Our MND Connect helpline can help direct you to our own and external services as needed.

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

Many carers have told us they tend to place their own needs after those of the person they support. It can be difficult to find time to look after your own needs when providing care. However, if you become overwhelmed or exhausted, you may reach a point where you are unable to continue in the caring role, even if this is what you wish. Ask your GP for a health check if needed.

“The needs of the other person can take over, so you feel you hardly exist anymore.”

See Section 8: *Looking after yourself for suggestions about how to care for yourself when caring.*

The following headings look at the support someone with MND may need and how you may be involved.

“What happens next? What can I expect to manage and what happens afterwards?”

Personal care and household tasks

See our guide: *Living with motor neurone disease* and our booklet: *Personal care for suggestions on how to manage everyday life with MND.*

As symptoms progress, you may find yourself taking on extra work or tasks you never expected to do.

This may include:

- household routines or gardening
- accompanying the person when travelling
- looking after finances
- being responsible for children
- increasing levels of personal care.

“I just hope I will be able to maintain the care that I am managing at the moment.”

Even if you enjoy caring, or family and friends help share the load, there may come a time when you need additional help because:

- the demands of care increase
- the person’s needs may become complex, requiring medical support
- there may be aspects of personal care that you or the person with MND prefer someone else to support
- you may need someone to provide care while you go shopping, run errands or take a break
- the person may need support both day and night and you need help to rest.

See Section 5: *What kind of support is available for details about emergency cover, respite care and other support.*

If you need professional support, adult social care services can arrange a needs assessment for the person with MND and a carer’s assessment for yourself (in Northern Ireland this is called a community care assessment). The aim is to work out what could help and how this can be provided.

See Section 4: *Carer’s assessment for details about how to arrange, prepare for and get the best possible outcome from your assessment.*

Further assessment by an occupational therapist (OT) can also help the person with MND remain independent for as long as possible. Support can be provided through equipment, assistive aids and adaptations to the home. This can help you as the carer too, by relieving some of the demands of daily care. Ask your GP or any member of the health and social care team about referral to an OT.

Attending appointments

The person you support may need:

- assistance to and from appointments if mobility is affected
- help to explain their needs if speech and communication are affected
- emotional support if the appointment involves a sensitive conversation.

Lots of professionals may be involved with the care of MND, which can mean lots of appointments. Even home visits by professionals can still be tiring and it can feel as if there is a constant stream of people at the house.



“We deal with so many people. We have a list on our fridge – there are about twenty professionals.”

At an MND care centre or network, or neurological clinic, a multidisciplinary team is usually available. This means more than one specialist is present, as part of a co-ordinated care system. This can be less tiring than lots of separate visits.

See Information sheet 3A: MND care centres and networks for details about how to access this type of care and Section 5: What kind of support is available?


Listing questions before appointments can help you cover everything you need to ask.

See our *Appointment queries* page at the back of this guide to help you. Additional copies can be downloaded at: www.mndassociation.org/carerguide or ordered from our MND Connect helpline.

If you make notes at each discussion for reference, date these and add the name of the professional. This can help if you need to query anything later. You can also ask to record what is being said on a smart phone.

Financial support

Financial support may be necessary to help with the extra costs of long-term illness and care.



“There are things that we need but are unable to get because we can’t afford them.”

We provide information about benefits and financial support, including guidance on work decisions if either of you are employed.

See Section 6: Work and financial support for more on employment, benefits, financial support and social care.

In time, the person you support may need help to physically manage their finances and access their bank account. Ask the relevant bank how to do this in the most helpful and appropriate way. The most effective way is for the person with MND to arrange power of attorney for you, where you have a legal authority to manage their finances.

See our publication: *End of life: a guide for people with motor neurone disease* for more about finances and power of attorney.

Movement and personal mobility

As the disease progresses, muscles stop working. This means the person can develop problems with grip, movement and mobility.

A huge range of equipment is available to help someone maintain independence for as long as possible. This can help you as their carer too. Devices such as adapted cutlery and dressing aids can assist daily living. Rails, walking frames, wheelchairs and hoists can support mobility. Some equipment is provided on loan by health and social care services.

See information sheet 11C – *Equipment and wheelchairs.*

See our guide: *Living with motor neurone disease for suggestions on how to manage everyday life with MND.*

It is important to plan ahead and consider future needs, as MND changes quickly. By the time equipment arrives, it may no longer be of use. To avoid frustration and costly mistakes, the person's needs should be assessed to ensure equipment is suitable.

Occupational therapists and physiotherapists can assess the person's needs and may be able to:

- suggest ways to make daily routines easier
- provide some items free through health and social care services
- advise about suitable additional items that you may need to source.
- advise on access to NHS Wheelchair Services and other providers

“My partner is much heavier than I am and I’m finding it difficult to move him despite the equipment we have been given.”

You may have difficulty assisting the person you support from place to place, such as from chair to bed. As well as using equipment and hoists, a carer's assessment may result in support from care workers at certain times of the day.

Training in moving and handling can also help you support someone's weight as safely as possible. At your carer's assessment, ask who can help with this type of training. They may suggest an occupational therapist, physiotherapist or a contact from a local organisation, such as a local carer's centre.

See Section 4: *Carer's assessment for details about how to arrange, prepare for and get the best possible outcome from your assessment.*

Adapting the person's home can make life easier for you both. Examples include:

- widening doorways for wheelchair access
- installations such as through-floor lifts
- converting a downstairs room into a bedroom.

An occupational therapist can help assess the home and advise on options. This is important to ensure any changes suit the needs of the person with MND, as mistakes could be costly and frustrating.

Try to think ahead to future needs, as MND can change rapidly. For example, a stairlift is helpful for someone using a walking frame, but may not be helpful if they use a wheelchair. A stairlift requires a wheelchair on each floor, and possibly a hoist to transfer between chair and stairlift. A through-floor lift or downstairs conversion may provide easier access for wheelchair use.

There may be funding to assist with installations and home adaptations, such as a Disabled Facilities Grant (DFG). Arranging funding can be a lengthy process, so it is worth looking into as soon as possible. This may feel too early, but it is important to plan ahead for adaptations so they are ready when the need arises.

See information sheet 10C – *Disabled Facilities Grants.*

Travel and transport

“While we could get out and do things together there were plenty of positives, companionship and trust.”

Travel can become difficult as mobility and disability increase. You may want to explore information about:

- wheelchair accessible vehicles (WAV)
- the Motability scheme, which can help to fund adapted vehicles and WAV vehicles for people with disabilities who receive certain benefits
- the Blue Badge Scheme, which enables people with disabilities to park closer to their destination, by using restricted areas or disabled parking bays
- local taxi services offering wheelchair accessible vehicles
- local transport schemes, such as subsidised taxi rides or Dial-a-ride for people with disabilities (your local authority can advise in England and Wales or your local health and social care trust in Northern Ireland)
- subsidised public transport, which may be available to carers (for example, you may be able to pay a reduced train fare if the person with MND has a disabled person's railcard and you accompany them as their carer)
- non-emergency ambulance or patient transfer services – check with the hospital or clinic concerned to find out what's available.

See our booklet on *Getting around*.

Physiotherapy and flexibility

If movement and mobility are affected by MND, the person will experience stiffness in muscles and joints. They may also have cramp, where muscles tighten suddenly. While MND does not usually cause direct pain, stiffening and cramp can be painful.

Exercise, assisted exercise or passive exercise (where you help the person by moving their limbs for them) can ease muscle stiffening and associated pain. It cannot reverse muscle weakness or slow down the progress of the disease, but where stiffness occurs, exercise may improve range of movement for a period of time.

“With gentle persuasion and exercise, my husband regained enough range of movement for me to wash under his arms again and dress him pain free.”

With MND, it is important not to over-exercise as this can cause fatigue. A physiotherapist with experience of MND should assess the person's needs, advise on a suitable exercise plan and review exercise routines as needs change. They can also advise you how to assist with this, keeping safety in mind.

See information sheet: *6A – Physiotherapy and 6C - Managing pain*.

If the person with MND still experiences pain, contact their GP or another member of their health and social care team for advice.

Speech and communication

Speech, gesture and facial expression can all be affected by MND. This can make it harder for the person to explain what they need.

Finding other ways to communicate takes patience and time for you both, which can affect emotions and relationships.

See Section 7: *Making sense of your feelings*.

“We just slipped into this home-grown sign language... he'd have a particular way of moving a hand or his eyes and we'd know. And even when he was slurring badly, we could make out what he was saying when no-one else could.”

Communication aids can help. Depending on the person's needs and preferences, simple aids such as a notepad and pen, word and image cards, or alphabet boards may be suitable. There are also high-tech aids, such as text-to-speech applications for computers, tablets and smart phones. Adapted switches and controls can help the person to access these in a variety of ways.

See our guide: *Living with motor neurone disease* which has a section on speech and communication.

If the person with MND has never used a computer or keyboard before, it is a good idea if they start practising before they really need communication aids. Whether using adapted switches or a keyboard, it can help to know how to move around the screen and use basic options.

If the person uses a high-tech aid, there is always a risk it might develop a fault or cannot be used for some reason. As a back-up, we recommend the person with MND practises with a simple aid too, such as an alphabet board.

As with all equipment, the person's needs should be assessed and reviewed if they change. Not all solutions suit everyone and some can be very expensive. Ask their GP or wider health and social care team for referral to a speech and language therapist, preferably with experience of supporting MND. This may also result in supply of communication aids through health and social care funding (statutory services)

We may be able to assist with equipment loan or an MND Support Grant where there is a waiting list or if statutory services have not been able to supply a suitable communication aid.

See Section 11: *How the MND Association can help you* for details about our Communication Aids service, equipment loans and MND Support Grants.

Swallowing difficulties

If the muscles in the mouth, face and throat are affected, someone with MND may experience swallowing difficulties. This can lead to issues with eating, drinking, saliva control and coughing.

The person with MND may experience:

- weight loss
- longer mealtimes
- tiredness
- thick or thin saliva
- drooling
- a dry mouth
- a weak cough or bouts of coughing
- mild or severe choking and aspiration (food or drink getting into the airways)

The person can ask their GP or another member of the health and social care team for referral to specialists, such as:

- a dietitian to advise on nutrition, types of food, supplements and food preparation
- a speech and language therapist to advise on swallowing techniques, food consistencies and thickeners to make drinks easier to swallow
- a GP, dietitian, speech and language therapist or a nurse specialist to advise on tube feeding.

Tube feeding is usually introduced by a hospital procedure known as gastrostomy. Once inserted, the tube can be used to top up or replace eating and drinking as required.

With a tube, the person may still be able to eat and drink by mouth for enjoyment, for as long as they feel safe to do so. They may choose to continue doing this at their own risk.

It is important to consider tube feeding as soon as swallowing difficulties begin. If the person decides to go ahead, it is better to introduce the tube before a significant amount of weight is lost.

Deciding whether or not to use tube feeding needs full discussion between the person with MND, yourself as the carer, and the health and social care team who support. If someone with MND does not wish to use tube feeding, their dietitian and speech and language therapist can support and advise.

See information sheets: 7A – Swallowing difficulties and 7B – Tube feeding.

See our *Eating and drinking* guide for guidance and easy-swallow recipes. Also <https://mytube.mymnd.org.uk> for videos about using tube feeding.

Tube feeding may need your support, but can reduce worry about the person getting the food and drink they need. It can also shorten mealtimes, which may have become tiring for you both, and the time you spend preparing foods in different consistencies. Tube feeding also avoids aspiration, where food and drink gets inhaled into the lungs, which may cause repeated chest infections.

“Pouring liquid feed down the tube, and flushing with water to clean, very quickly became part of the daily routine. It doesn’t disrupt or prevent any activity.”

Some carers have told us they feel guilty eating in front of someone who is tube fed. They often rush their own mealtimes or eat alone. If this affects you, try to discuss this with the person you support. You may find they prefer life to be as normal as possible and for you to feel relaxed at mealtimes.

Tube feeding in advance of a meal can also help the person to feel more comfortable at social gatherings, if eating and drinking have become difficult to manage.

Breathing support

MND can affect the muscles involved in breathing.

The person you support may need referral to a respiratory team for assessment if they show any of the following symptoms:

- shallow breathing or feeling breathless
- difficulty breathing when lying flat
- repeated chest infections
- a weak cough, sniff or voice
- disturbed sleep
- morning headaches
- nightmares or hallucinations
- daytime sleepiness or feeling very tired
- confusion, with poor concentration or memory
- poor appetite.

Ask their GP or a member of the health and social care team for advice and referral.

Assistance can include:

- breathing exercises and physiotherapy
- advice on body positioning
- assistance for a weakened cough
- medication
- mechanical breathing support through ventilation.

Ventilation is not suitable for everyone. However, where appropriate, it may help relieve anxiety about breathing, improve sleep and reduce tiredness.

For more detail, see our range of information sheets: 8A – 8D about breathing and ventilation. Also <http://mybreathing.mymnd.org.uk> for videos about using ventilation.

MND Just in Case kit

We provide an MND Just in Case kit to help if someone with MND experiences a sudden change with symptoms such as breathlessness, anxiety, coughing or choking. Most people never have to use the kit, but it can be reassuring to have it nearby.

The GP of the person with MND can order the kit free of charge from our MND Connect helpline. They should then prescribe suitable medication to keep inside the box. The box has two sections:

- one for medication that can be used by a doctor or nurse
- the other for medication that carers can give to the person with MND (which you must be shown how to use by the GP or district nurse).

Our helpline can be contacted as follows:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

“My own experience has shown that you’re not always prepared in time or symptoms are not spotted early enough. In my husband’s case, his breathing problems were too far advanced for him to use treatments like non-invasive ventilation effectively.”

Tiredness

Tiredness and extreme fatigue can be a common concern with the disease. This can be worrying and you may find yourself having to provide increased levels of support.

There may be various reasons why the person with MND is getting so tired:

- as muscles grow weaker, everyday tasks can take longer and need more effort
- the diagnosis and daily challenges of MND can be emotionally exhausting
- swallowing difficulties may cause the person to eat less, so they are not getting the nutrients they need (see earlier heading, *Swallowing difficulties*)
- breathing problems may lead to disturbed sleep and tiredness (see earlier heading, *Breathing support*)
- there may be another underlying condition that needs to be assessed.

If the person is frequently tired, ask their GP for advice.

Where possible, plan social activities at times when the person with MND tends to feel most alert. Being flexible with routines can help. Focus on essential tasks and let others go if need be, as this may give you both more time to do the things you really want to do.

“I never feel like I have enough time to please everyone.”

You may feel extreme tiredness as the carer too and need to be aware of your own energy levels. If your own fatigue is persistent and you find it increasingly hard to cope with the demands of the caring role, ask your own GP for a check up.

See Section 8: Looking after yourself.

You may need support. Ask for a needs assessment for the person with MND and a carer’s assessment for yourself to find out what help is available. If you have both already been assessed, ask for a review of your needs.

See Section 4: Carer’s assessment.

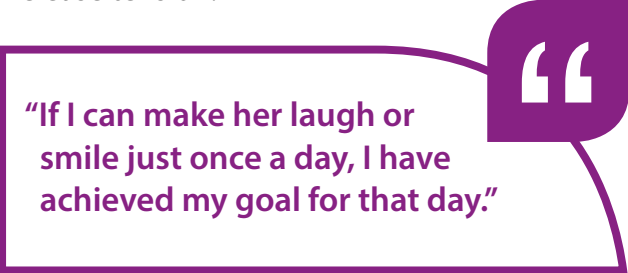
Emotional support

A diagnosis of MND can be devastating, both for the individual and yourself as partner, relative or friend. Sometimes there can be a sense of relief after a period of great uncertainty, but most people, including the wider family and friends, need time to adjust. Intense emotions are likely to be experienced.

Emotions can be very mixed too, often including sadness, grief, guilt, anger and fear. Each individual may have a different response, depending on their age, circumstances, culture, beliefs and relationships.

See our booklet, [Emotional and psychological support](#).

Open discussion can provide 'permission' for people to express emotion together and find ways to support each other. Laughter and tears are natural responses and can help to release tension.

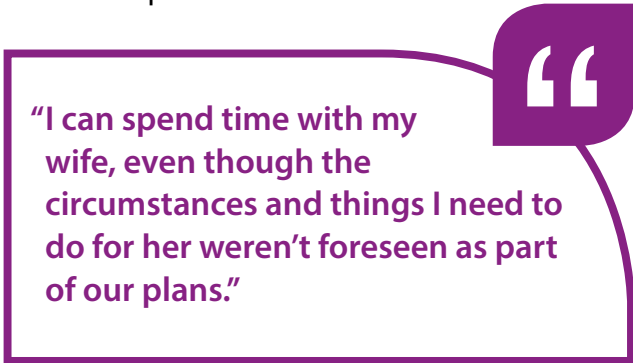


"If I can make her laugh or smile just once a day, I have achieved my goal for that day."

If strong emotions persist and become distressing, a GP can advise. Counselling can be helpful. You may find this easier to tackle together and referral to a hospice or specialist palliative care team can be valuable. They provide emotional support, as well as symptom control and practical guidance, all of which can ease anxiety and help maintain the best possible quality of life.

If your relationship with the person who has MND was strained before diagnosis, it may be important to seek professional help. The health and social care team can support difficult discussions and help you both manage the way ahead. Again, counselling may help, or you may need more support with care, or alternative care arrangements.

Despite the shock and challenges of MND, for many it can be a time for closeness and building memories. This can help to balance emotions with positive events and shared experiences.



"I can spend time with my wife, even though the circumstances and things I need to do for her weren't foreseen as part of our plans."

Emotional lability

Some people with MND find they laugh or cry at inappropriate times, known as emotional lability (sometimes called pseudo-bulbar affect). The person may laugh when upset or cry when happy. This is an abnormal motor response caused by the disease and often reduces over time.

It can be difficult to control and distressing for the individual and those around them. A GP can advise, but may not be familiar with this symptom. If so, ask an appropriate member of the health and social care team who has experience with MND, as there may be medication to help.

See our booklet [Emotional and psychological support](#).

It can help once you and the person with MND fully understand what is happening. Having accepted that these responses are a symptom of the disease, they usually become easier to manage. Rather than trying to avoid them happening at all, you may find shared ways to deal with the effects, which can help the person feel more secure. This may calm situations.

Changes to thinking and behaviour

About 1 in 2 people with MND are thought to have some changes to thinking and behaviour (known as cognitive change). This number increases in the later stages of MND. In most cases, the changes are mild and have little effect on daily life. Where the changes are more severe, the ability to make reasoned decisions may become more difficult.

“He relied on people asking him simple, direct questions. You had to give just one choice at a time or he’d get confused.”

The individual is unlikely to be aware of the differences, but you or another relative or friend may notice first. For example, they may show signs of:

- personality change
- apathy
- inappropriate behaviour
- repeated behaviour
- poor concentration
- problems with reading and writing
- aggression.

Some changes may be the result of fatigue, poor sleep or depression, but do seek help if you are concerned. Ask the person’s neurologist for advice. There are screening tests to work out if the way they think has changed and more detailed assessments to review the level of change. Guidance and support can be given to help ensure appropriate care and safety in the home.

About 1 in 10 people with MND who experience changes to thinking and behaviour develop a type of dementia called frontotemporal dementia (FTD). This can be very difficult for you to manage as a carer and additional support is likely to be needed. As MND and FTD are rare, not all professionals or care workers will understand the needs that may arise.

Ask for guidance from a professional experienced in MND, such as the person’s neurologist. They can refer you to specialists.

See our booklet, *Changes to thinking and behaviour with MND*.

Medication

With MND, someone may take medication to:

- help with problems such as thin or thick saliva
- ease or control other MND symptoms
- manage other conditions or anxiety.

See earlier heading *Breathing support* for details about our MND Just in Case Kit to help with sudden breathlessness and anxiety.

Riluzole is the only licensed drug in the UK known to have a moderate effect on the course of MND. It is thought to slow the disease by several months. If riluzole is suitable for the person you support, ensure the prescribing doctor is aware of any other medications.

See information sheet 5A – *Riluzole*.

There may be soluble or liquid medicines if the person finds it difficult to swallow tablets. Many liquid medicines can also be given via a tube if the person has decided to use tube feeding to top-up or replace meals by mouth.

Always read instructions carefully when giving medication. Ask a GP or district nurse if in any doubt about combining medicines, using over-the-counter remedies or whether to give medication through a feeding tube.

Skin care and pressure relief

If mobility is affected, the person with MND may be in one position for long periods of time. This may cause skin discomfort.

Repositioning at regular intervals can help, but you can ask their GP, district nurse, occupational therapist and physiotherapist for guidance. They may be able to provide specialist equipment to help, such as pressure relief cushions or air mattresses.

If the discomfort continues, the person may be referred by a member of the health and social care team to a specialist nurse, palliative care team or local hospice for symptom control. They can help prevent skin sores from developing.

Planning ahead for future care

Please note, this short section includes information about later stages and end of life decisions. You can return to this later if you do not want to read this now.

MND is life-shortening and in the later stages, care can become complex. Being prepared and well-informed can help the person with MND to receive future care in the way they would prefer. It can also help you get the help and support you may need.

Making plans can be reassuring, as it enables choice and more control over what happens next. If you wait until point of need, you may find that services, equipment or even funding are difficult to arrange at short notice.

Future care arrangements will affect both the person with MND and yourself as their carer. Try to have discussions about this together, along with the health and social care professionals who support. They can help during difficult conversations and advise on how to plan ahead.

Once plans have been made, you can both get on with living. You may find it brings peace of mind knowing that arrangements have been made and agreed.

“He wanted to make sure that everything was set up and in order...I found this really hard because I knew what it represented, but that was his way of facing it.”



In addition to getting financial affairs in order and making a will, the person with MND can:

- make an advance care plan to guide professionals about preferences for future care and location of care
- create a legally binding advance decision to refuse or withdraw treatments the person does not want, in specific circumstances (which can include wishes about resuscitation)
- ask you or someone else to make future decisions on their behalf, if needed (usually through Lasting Power of Attorney in England and Wales or Enduring Power of Attorney in Northern Ireland).

These arrangements only become active if the person becomes unable to make decisions or communicate for any reason. However, these plans ensure things happen as the person would wish. This can help you too – with written guidance, you may find it easier to provide support, knowing you are following their choices.

See Section 5: *What kind of support is available?* for details about NHS continuing healthcare, which can assist complex needs.

When you feel ready, we provide comprehensive information about end of life decisions, including aspects like arranging power of attorney.

See our publication, *End of life: a guide for people with motor neurone disease.*

Key points

- Try to anticipate change as much as possible, as equipment and services can take time to arrange.
- Assessments not only lead to general support, but may help empower the person with MND to remain independent for as long as possible.
- Plan joint activities when the person with MND tends to feel most alert.
- If symptoms need specialist help, ask the person's GP or another member of the health and social care team for a referral.

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:

- 2B: Kennedy's disease
- 3A: MND care centres and networks
- 5A: Riluzole
- 6A: Physiotherapy
- 6B: Complementary therapies
- 7A: Swallowing difficulties
- 7B: Tube feeding
- 8A to 8D: our range of sheets on breathing and ventilation support for MND
- 10A to 10G: our range of sheets on benefits, financial support and social care
- 11C: Equipment and wheelchairs
- 14A: Advance Decision to Refuse Treatment (ADRT)

From our research information:

Research sheet B:

- Part one – Introduction to inherited motor neurone disease
- Part two – Genetic testing and insurance
- Part three – The options available when starting a family

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 and future care.

Personal care: ways to prolong independence in personal routines for the person with MND.

Emotional and psychological support: therapies that can help both the person being supported and the carer.

Changes to thinking and behaviour with MND: how to get support if you think someone with MND is showing these changes.

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 who support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

3: Your rights as a carer



This section provides an overview of your legal rights as a carer and how these are governed.

The caring role can be challenging. It is important to know your rights and entitlements, which can help you get the support you may need, either now or in the future.

No matter how willing you are to provide care for your partner, relative or friend, you may still need to be supported in this role. You may need financial support, help with care tasks, breaks to ensure your own wellbeing or ways to maintain your own life beyond the caring role.

To receive support, your needs have to be considered. This is done through a carer's assessment arranged with your local authority in England and Wales, or health and social care trust in Northern Ireland. This section looks at how your right to assessment is governed.

See Section 4: *Carer's assessment for more details about how assessment works.*

Your rights as a carer are governed in slightly different ways depending on where you live in the UK.

As a charity, we support people affected by MND in England, Wales and Northern Ireland. The following information looks at carer rights in these countries. If you live in Scotland, please contact MND Scotland for guidance.

See Section 12: *Useful organisations for full contact details.*

What are my rights as a carer in England?

In England, the Care Act 2014 sets out carers' legal rights to assessment and support. This overview explains the main points. Search for Care Act 2014 at: **www.legislation.gov.uk**

See also Section 9: *Support for children and young people for guidance about rights for young carers.*

The Care Act means the rules for each local authority are consistent across England. Local authorities have a duty to support 'where an individual provides or intends to provide care for another adult and it appears that the carer may have a level of need for support'.

Your views, wishes and feelings as a carer should be considered at assessment. This must take into account your ability and willingness to continue caring, as well as any employment, education, training or leisure needs.

Do I qualify as a carer in England?

The Act means it is a legal duty for local authorities in England to promote carer wellbeing when making decisions about their needs. This means they must do what they can to 'prevent, reduce and delay' needs from developing.

This means all carers are now entitled to assessment. You may be referred by a member of the health and social care team or you can contact adult social care services through your local authority.

See Section 4: *Carer's assessment for details about how to prepare for an assessment and what to expect.*

Your wellbeing as a carer might be affected in various ways, such as not getting time to eat well or not being able to use recreational facilities that you previously enjoyed. It may also include your ability to work or remain responsible for the care of a child.

The person you support should also have a needs assessment to determine how they can be helped. You can have a joint assessment if you both agree.

Do I need to pay for any support as a carer in England?

Assessments should be carried out regardless of your financial circumstances, amount of care you provide or any support already being received.

Once assessed, your local authority must work with you on your support plan and how your needs could be met. This can include information, guidance and services. Some services are free for carers, but you may be financially assessed for others. This tells you how much you might need to pay and how much the local authority might pay. You cannot be charged for any care, services or respite supplied directly to the person you support, even if this helps you (for example, a care worker providing personal care). The person you support is financially assessed for any care they receive.

Information about support for carers in England

The Care Act 2014 covers how local authorities in England should provide comprehensive information and advice about social care and support in their area, for adults and their carers.

They should be able to tell you about:

- the way their systems work
- types of care and support, and the providers available
- how to access independent financial advice, including for benefits and financial support
- how to raise concerns about a person's safety or wellbeing.

Contact your local authority for more assistance. You can also find a wide range of content about adult social care from the online government service at: www.gov.uk or search for carer rights at: www.nhs.uk

What are my rights as a carer in Wales?

In Wales, carers' rights are protected under the Social Services and Well-being (Wales) Act 2014, that came into being 2016. Find resources that explain these rights at <https://gov.wales/carers-rights> or find the full Act at www.legislation.gov.uk

The Act describes well-being as:

- making sure you know about your rights and what they mean for you
- being healthy
- protection from abuse, harm and neglect
- having access to employment, education, training, sports and leisure
- having positive relationships with family and friends
- being part of the community
- having a social life
- having a safe and secure home.

See also [Section 9: Support for children and young people for guidance about rights for young carers.](#)

Do I qualify as a carer in Wales?

If you provide a lot of ongoing support, you should qualify. Even if you provide a limited amount of support and this has a big impact on your life, you can still be assessed. For example, you may be juggling work and care, which can be difficult. If the person you look after does not want to be assessed for help they need, you can still be assessed to consider any help you may need as the carer.

Once identified as a carer, you should be informed of your rights and your entitlement to assessment. Whether you wish to continue caring or not should be considered at assessment, and whether you need a break for education, training or a leisure activity.

As with the Care Act for England, The Social Services and Well-being (Wales) Act requires the person conducting the assessment to pay regard to your views, wishes and feelings as a carer. This must take into account your ability and willingness to continue caring, as well as any employment, education, training or leisure needs.

Local authorities will have a duty to meet your eligible needs as a carer within an agreed plan, which should be regularly reviewed.

Do I need to pay for any support as a carer in Wales?

Your local authority can charge for agreed care or support provided, where there is a cost to meet your needs. A financial assessment will take place to work out how much you may need to pay towards any arranged services.

Information about support for carers in Wales

As in England, there is a duty for local authorities and Health Boards in Wales to provide people with information and advice relating to care and support.

Contact your local authority for more assistance. You can also search for a wide range of content about adult social care from the online government service at:

www.gov.uk

What are my rights as a carer in Northern Ireland?

If you live in Northern Ireland and provide a 'regular and substantial amount of care' for someone aged 18 or over, you have the right to an assessment of your needs as a carer. This is governed by the Carers and Direct Payments Act 2002. Find more information about the Act and your rights at:

www.nidirect.gov.uk/articles/overview-carers-rights

Legislation in Northern Ireland places a responsibility on health and social care trusts to inform carers of their right to an assessment of their needs. They should consider a carer's interests, such as work, study or leisure. They also have power to supply services directly to carers to help them in their caring role.

Contact your local health and social care trust to ask about assessment. They also have a responsibility to make sure a young carer's own wellbeing is looked after and that they receive the necessary support.

See also Section 9: Support for children and young people for guidance about rights for young carers.

Do I qualify as a carer in Northern Ireland?

There is no set definition of 'regular and substantial care'. However, if the support you provide affects you because of your age, health, work, studies, other activities or commitments, you may need to be assessed. A carer's assessment means social services will look at your situation to see if you are entitled to any services that could make caring easier for you.

Do I need to pay for any support as a carer in Northern Ireland?

In Northern Ireland, the Carers and Direct Payments Act allows for charges to be made for services to a carer following a carer's assessment. However, this is not common practice.

If you are asked to contribute, you will be financially assessed to work out the level of payment required.

If services, such as respite care, are provided for the person you support, they can be charged separately for this help. Home care services (known as domiciliary care services) are usually provided free of charge in Northern Ireland.

Information about support for carers in Northern Ireland

Contact your local health and social care trust for details about carer support in your area. You can view online government information about carers' rights at: www.nidirect.gov.uk/articles/overview-carers-rights

What about my employment and benefit rights as a carer in the UK?

If you are a carer in employment, you have the right in the UK to request flexible working and time off at short notice to help you in your caring role. If you wish to continue your employment while caring, these approaches can help. This may be important to you for career or financial reasons, or to maintain work and social networks.

Your rights in this area are governed by the Work and Families Act 2006 and the Employment Rights Act 1996, and in Northern Ireland by the Work and Families (NI) Act and the Employment Act (Northern Ireland) 2016.

You may also be entitled to a range of benefits for financial support. If you have not claimed benefits before, it may feel uncomfortable to claim these at first. However, it is your right and may help if you reduce your working hours or decide to leave work during the caring role.

See Section 6: *Work and financial support* for more details about how to manage employment and caring, and the benefits that may be available to you.

Key points

- Ask for a carers' assessment if you have not been offered one. Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland.
- Be aware of your rights as a carer, whether you live in England, Wales or Northern Ireland. This can help you get an assessment, which may help supply the support and information you need.

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:

- 10A: Benefits and entitlements
- 10B: What is social care?
- 10C: Disabled Facilities Grants
- 10D: NHS continuing healthcare
- 10E: Work and MND
- 10F: Personal Health Budgets (England)
- 10G: Support for families with children

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.

Personal care: our booklet about daily routines with MND.

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.

Benefits Advice Service:

The MND Association Benefits Advice Service provides free, confidential and impartial guidance on any benefits you may be entitled to receive.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: Through the website contact page at: www.mndassociation.org/benefitsadvice

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

Useful organisations:

You may also want to discuss carer rights with organisations who specialise in this area, such as:

- local carer centres, groups and charities provide support and guidance and are usually listed by your local authority
- national organisations such as the Carers Trust and Carers UK.

See Section 12: *Useful organisations* for suggested organisations offering support for carers in England, Wales and Northern Ireland.

4: Carer's assessment

This section looks at how to get your needs assessed as a carer and how this can lead to support.



What is a carer's assessment?

It may feel difficult to ask for help, but caring can be challenging and your needs matter too. A carer's assessment can lead to support, to help you maintain your wellbeing.

"It's about finding solutions to problems to enable life to continue as positively and optimistically as possible."

A carer's assessment is an opportunity to discuss the impact of the caring role, which is important. If you ignore your own needs and care demands increase, you could reach crisis point. An early assessment not only provides possible support, but can help you plan how to manage unexpected situations. Even if you are coping well at the moment, it is worth being assessed to find out how to access services you might need in the future.

The assessment does not judge how capable you are as a carer, but helps professionals work out how to make your caring role easier. Depending on your needs, you may receive guidance, information or services, as appropriate.

If you have not been offered a carer's assessment, you can ask for one to be arranged. Contact adult social care services through your local authority in England and Wales, or through your local health and social care trust in Northern Ireland (we will use the term 'local authority or trust' for the remainder of this section).

If you agree, the assessment can be done by telephone or online in England or Wales, but you can ask for a face-to-face assessment. This allows for a more open discussion and can take place at an agreed location or at home. You may have someone with you to support, if wished. In Northern Ireland, assessment is occasionally completed by telephone, but usually face-to-face (not online).

The assessment results in an agreed support plan, which may include:

- provision of services or direct payments for you to arrange services of your choice, to meet the needs identified in your support plan
- referrals to other support, such as benefits advice
- plans for respite care and carer breaks
- assistance with travel
- suggestions for counselling
- information about support groups and voluntary support organisations.

The assessor should look at innovative ways to meet your needs if necessary. Be aware that there may be limits to the services that can be provided and you may have to contribute towards costs, as agreed through financial assessment. However, your leisure, training and work needs should be considered.

"I am a full-time carer, a full-time dad, a full-time homemaker and I'm trying to find work...there aren't enough hours in the day and not enough energy to do everything."

Do I qualify?

You usually qualify for support if you provide necessary care to someone and this is likely to impact on your wellbeing.

Being a carer does not guarantee access to services, but assessment helps you find out what is available.

See [Section 3: Your rights as a carer](#).

Who attends a carer's assessment?

The assessment is usually carried out by a social worker, or an appropriate representative or contractor for adult social care services.

You can have a friend or someone to support you at the assessment if you wish.

The person you support can also have an assessment of their needs. There is a duty to ensure their eligible needs are met and services supplied to them may help you as a carer too.

If you both agree and find it comfortable to discuss the challenges you face as a team, a combined assessment can be carried out at the same time. You may prefer to have your carer's assessment on your own.

"It can be hard to talk about your issues if the person with MND is present."

If the person with MND sees themselves as more able than they really are, it may be difficult to 'tell it like it is' when they are listening. If you are finding it hard to cope in the caring role, it may also feel difficult to discuss concerns in front of the person you support.

"There's not much a carer can do when the person with MND tells health and social care professionals, 'I can manage. I don't need more support at the moment.' Also, we carers understandably want to praise the person's bravery and initiative, so we don't always ask for help either."

If you have a separate assessment, try not to feel guilty about doing this without the person you support. It is important to have your needs addressed.

Care needs increase with MND and can be very challenging. You should not have to wait until there is a crisis before being offered assistance.

If someone 18 or under is involved in support for someone, they are known as a young carer. They can also have their needs taken into consideration with a young carer's assessment.

See [Section 9: Support for young carers for details about support for young people and rights for young carers](#).

What do I need to think about?

You may find it difficult to think about yourself when caring. If you feel under pressure, it may seem there is never enough time to get everything done and you may place your own needs second.

"Contacting adult social care services to ask for a carer's assessment seems a very useful thing to do."

Try to include a broad picture of your life at the assessment, including family, leisure and work, as this will help the assessor. They can advise how to balance other activities and routines with the caring role.

The assessment can help you consider the following questions:

- Do I need help?
- Am I willing and able to carry on caring?
- Can I continue to provide the same or increasing levels of care?
- How will caring affect my life?
- Are there any services that could assist me?

You may be happy to continue as a carer, but there could be circumstances that prevent this (for example, if you become ill, through family pressures or other reasons). Try to think ahead so that contingency plans can be made.

If you have children or other dependants, this may affect the type of support you need. Let the assessor know of any other responsibilities you have. The person you support may also be a carer for someone else, which may need to be discussed and alternative care provided as needed.

As the assessment does not judge your capability as a carer, there is no need to prove how well you cope or 'put on a brave face'. Try to have an open discussion about your needs and whether anything might cause your caring role to break down. Explain when you feel under pressure and what could help, to get the most suitable support for you.

It can help to explain the difference a particular type of support would bring, as this helps show the outcome you hope to achieve, rather than just talking about services.


How do I prepare for my assessment?

The thought of being assessed, and dealing with yet more information, may feel overwhelming on top of everything else. However, you may receive a pre-assessment form to complete before the appointment, which gives you an opportunity to make notes and feel more prepared. If not, ask to see a blank assessment form.

The exact content of any pre-assessment or final assessment forms can vary, as each local authority or trust may use their own version. However, the questions covered will be very similar. If you have a concern that does not appear to be included, you can still raise this with the assessor.

See the *Carer's assessment preparation form* in Part 4 of this guide, which can help you identify some of the areas that may be covered at assessment.

Keeping a diary in the run-up to the appointment is useful. If you make notes about your daily routines over a period of time, it provides good evidence for the assessor. It may also show how the person's care needs are increasing, which can help with forward planning.



“Keeping track – keeping a log. When? Time is taken up with tasks and when it’s not, you take a breather.”

It may feel difficult to track care tasks when you're so busy doing them. However, even if you only do this for a week, it can help you provide evidence at your carers' assessment. You don't need to write a lot of text, just note down each task you do, when you do it and how long it takes. This may help you access appropriate support to meet your needs.

See the *Care summary* in Part 4 of this guide, to help you track care tasks.

Before your assessment, consider how the caring role affects your:

- health and wellbeing
- relationships and family
- housing and living environment
- work and finances
- hobbies and interests.

If you are willing and able to provide the majority of care, be clear about the level of support you can continue to manage. This is particularly important if you are combining work and care, or if you have children or other dependants who also need your support.

An early assessment and the following questions may help you think more about your needs:

How I feel

- Am I getting enough sleep?
- Is my health affected?
- Do I get enough 'me time'?
- Can I go out if needed or wanted?
- Are other relationships affected?

Being a carer

- Does the person with MND need more support than I can give?
- Do I want to continue being a carer?
- Are there any changes that could make caring easier?
- Will I be unable to continue caring without support?

Further questions to ask at assessment

- What services can help me take a break?
- Where can we find emergency care cover if I am unable to support for any reason?
- How do I plan for urgent situations?
- Can I get support from other carers?
- Can I get any help with household tasks?
- Can I get any help with personal care during the day or night?
- Where can I get information about benefits and financial support?
- Where can I get information about balancing work with caring?
- Is there training on carer tasks?

See Section 5: *What kind of support is available?* for more information about emergency care cover and planning for urgent situations.

What happens at a face-to-face assessment?

You may decide to complete a self-assessment form, without an assessor. However, at a face-to-face assessment, the assessor will ask questions and help you:

- think about the help and support you may need
- find out which services and support may be available
- make decisions about the future.

The assessment form enables the assessor to record notes and provide you with your support plan, but does not represent the assessment process in itself. The focus should be on open discussion about your caring role to work out the support you need.

If you need further information on subjects such as benefits, leisure activities, education, training or work, you should be directed to other organisations or agencies for appropriate help.

Your assessment will review any risk of your caring role breaking down. For example, you may find it difficult to fit work commitments around the role. Or, there may be a more serious risk, such as health problems that could result in your hospital admission. Reviewing risk is particularly important with MND, as the disease will progress, which means the care demands will increase.

Following the assessment, you will receive a written support plan. This identifies your needs and any information, services or support that can be provided. Adult social care services should also liaise with other schemes on your behalf where relevant, such as housing.

The support plan will include recommendations, as agreed with you, such as:

- help with household tasks
- help to get around, for example, taxi fares
- technology to help you stay in contact with the person you support, or with services, such as a mobile phone or computer if you cannot easily access a computer elsewhere
- help to improve your health and wellbeing, such as a gym membership.

You should be offered an opportunity to give feedback about the assessment and raise any concerns you have.

Do I have to pay for carer services?

You may receive services free of charge or have to pay towards services you receive.

Where agreed services are chargeable, you will be financially assessed to see how much you need to pay (if anything).

The financial assessment will look at your income and capital (including any share of joint income or capital). This does not include the value of any owned property.

There is a financial limit known as the threshold, which will be explained to you.

If your income or capital is above the limit, you can still ask for your needs to be met. In this case, you can be charged for both the services provided and the cost of arranging and managing those services.

If required, you can have services arranged for you. However, where financial help is given for either part or all of the cost, you should be offered the choice of direct payments. These payments mean you can choose your own services, if you wish. This could include a wide range, such as gym membership and evening classes, or help with gardening and housework. Be aware that with direct payments, you are responsible for the money received and need to keep records.

See Further information at the end of this section about our publications on direct payments and other financial support.

You cannot be charged for services provided to the person you support (even if they help you), and the person you support cannot be charged for services provided to you.

You may also be able to claim certain financial benefits as a carer, such as Carer's Allowance. If you receive Carer's Allowance, it is not usually included as income in financial assessments.

See Section 5: Work and financial support.

See Further information at the end of this section about our publications on benefits and other financial support.

Northern Ireland

Please note that in Northern Ireland charges can be made for services to a carer following a carer's assessment. However, this is not common practice. If you are asked to contribute, you will be financially assessed to work out the level of payment required.

Services for the person you support

A needs assessment for the person you support looks at needs arising from their illness or disability. They will receive a care and support plan recommending information, services and support appropriate to their needs. This usually helps you as the carer too, by reducing the care demands you have to meet. It may include:

- adaptations or equipment at home to make it more suitable for limited mobility or other disability
- personal care at home by a care worker
- a temporary stay in residential care or respite care
- replacement care at home, so you can have a break
- meals delivered to their home or laundry services
- a place at a day centre
- assistance with travel.

If a care and support plan is agreed for the person with MND, they will be subject to a financial assessment to see how much they need to pay (if anything).

For example, respite care is usually funded as a care service for the person needing support, which would be considered as part of their financial assessment. You benefit by taking a break, but would not be financially assessed for this.

However, if you are given financial help to take a holiday away from home, this would be included in your financial assessment as direct support for you. This type of support will depend on your circumstances and what your local authority or trust can offer.

Northern Ireland

If services, such as respite care, are provided for the person you support, they can be charged separately for this help. Home care services (known as domiciliary care services) are usually provided free of charge in Northern Ireland.

What if something goes wrong?

Every local authority or trust is required to have a complaints procedure. If you are not satisfied with their response to any query or concern, you can make an official complaint.

The following may help guide you.

My carer's assessment has not been arranged or has been delayed:

Contact adult social care services through your local authority or trust to find out why. Let them know if your situation has become urgent or if the needs of the person you support have increased. Ask for an assessment date to be confirmed.

I filled in an assessment form and have been refused services:

Contact adult social care services through your local authority or trust and point out that you have not had a face-to-face assessment. You should be given an opportunity to meet with a social worker or other qualified representative to discuss your needs. This may help you provide more details about the challenges you face to gain the support you need.

The person I support has refused any external services or support:

Sometimes the person being supported may refuse outside help. This can be difficult, as it may leave you with little or no support as the carer. If this happens, your local authority or health and social care trust must consider how they can assist you. Contact them to discuss how else they can help.

I am unhappy with my carer's assessment:

If you are concerned about the way you were assessed or the outcomes in your support plan, contact adult social care services through your local authority or trust. Discuss the matter first, as there may be a simple solution. If you are not satisfied by their response, you can make a formal complaint. If your complaint is on behalf of the person with MND, you must have their consent if they are able to provide this.

My situation has changed or got worse:

Your support plan should be reviewed at an agreed date, but you can contact your local authority or trust at any point if you need to be reassessed. However, the more detail you provide about the progression of the disease at the first assessment, the more chance there is that future needs will be considered in your support plan. Making notes about the support you provide can help with this, even if you only do this for a week or two.

See earlier heading [How do I prepare for my assessment?](#) for details about tracking care demands to support your assessment.

I need help with my carer's assessment:

You can ask a trusted person to help you and act as an advocate, which means they can also attend the assessment with you. If you feel overwhelmed by the idea of a carer's assessment or by a poor result, it may help to discuss this. If you are in contact with one of our Association visitors, they can offer support. You can also contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Key points

- Your carer's assessment does not judge your ability, but helps identify how you might need support to continue the caring role and maintain your own wellbeing.
- Where services are agreed for either the person you support or yourself as the carer, you should be told about any charges before services have been arranged.
- You cannot be charged for services provided to the person you support (even if they help you), and the person you support cannot be charged for services provided to you.
- You and the person you support can be assessed together or separately. Ensure you let the assessor know which you prefer before any appointments are made.
- When being financially assessed, only your own income and savings (or part-share of joint income and savings) are usually taken into account. The value of any owned property is not included as savings.
- If you or the person you support refuse to do the financial assessment, you will be charged in full for services arranged.

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:

- 10A: Benefits and entitlements
- 10B: What is social care?
- 10C: Disabled Facilities Grants
- 10D: NHS continuing healthcare
- 10E: Work and MND
- 10F: Personal Health Budgets (England)

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.

Personal care: our booklet about daily routines with MND.

Motor neurone disease checklist: a form to help a person with MND think about their care needs.

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.

Benefits Advice Service:

The MND Association Benefits Advice Service provides free, confidential and impartial guidance on any benefits you may be entitled to receive.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: Through the website contact page at: www.mndassociation.org/benefitsadvice

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

We have information to help professional care workers provide the best possible support to people with MND. See our:

Caring for a person with motor neurone disease: a guide for care workers

Care worker online module: our training for care workers at:

www.mndassociation.org/online-courses

5: What kind of support is available?



This section looks at the types of care and support available to help you in the caring role.

“The main focus appears to always be on the person with MND. Carers appear to be left to carry on with little or no support.”

Types of care

MND support is wide ranging, but it is important to realise this can assist and guide carers too. You are an unpaid member of the health and social care team, so do ask questions if you need to and offer your viewpoint when you think it can help.

“It’s difficult to find your own path and plan ahead if you are unaware or unprepared for what may or may not happen. Usually it happens before you realise it.”

You understand how the disease is affecting daily life for the person with MND – and for yourself. Professionals should seek your input at appointments and the more they know, the more appropriate help and advice they can give.

The types of care include:

- your GP and community health team
- specialist healthcare for MND
- MND care centres and networks

- adult social care services
- specialist palliative and hospice care
- respite care
- residential and nursing care homes
- emergency and urgent support
- care following a hospital stay
- NHS continuing healthcare
- support from the MND Association
- support from other organisations
- support from other people affected by MND.

Health and social care services can vary across regions and sometimes there may be a waiting list for support. However, where possible, an early referral can help build a relationship. In urgent situations, this means needs and wishes will already be known.

This section provides an overview of available care, to explain:

- who is involved
- what each type of support does and how this can help
- how to access that help
- whether or not you need to pay.

Who is involved?

Before looking at the types of care on offer, it may help to consider the different health and social care professionals who make up these services. You may have contact with a large number of professionals, which can be bewildering.

“It is extremely confusing as to who has responsibility for which service.”

The following list explains the main contacts usually involved with MND, but you may meet others depending on your needs.

They may be part of:

- the community healthcare team
- a multidisciplinary team linked to an MND care centre, network or other neurology service
- a specialist ward in a hospital or clinic.

Although their primary aim will be the care of the person with MND, they can also answer your questions as a carer.

“It should be stressed that often the carer knows more about the person with MND’s personal needs than the professionals.”

GP: Your local doctor or ‘general practitioner’, is a central medical contact. They can help diagnose, prescribe medicines, maintain medical records, provide information and guidance, and refer you or the person with MND to specialists when needed.

Consultant neurologist: A doctor who specialises in the brain, spinal cord, nerves and muscles. They are experts on conditions such as MND and usually work with other medical consultants to ensure people with MND receive the best possible medical care.

Other consultants: As well as seeing a neurologist, someone with MND may see other consultants as needed, such as a respiratory consultant about breathing support or a palliative medicine consultant.

Specialist nurse: A nurse who specialises in a relevant field – often in neurology, with expert knowledge of conditions such as MND.

MND care centre co-ordinator: The main contact at an MND care centre or network, often a specialist nurse or other health professional. They help link people with the multidisciplinary team, community services and the MND Association. A similar role may exist in other neurological teams.

Community or district nurse: A nurse who works closely with your GP and is likely to visit the person with MND as the disease progresses. They can assist with medication, monitor and treat symptoms, help with prevention of pressure sores, provide certain items of home nursing equipment and advise on local services.

Speech and language therapist (SLT): These therapists assess speech and communication difficulties. They also work with people who have problems with eating and swallowing. Following assessment, they can provide guidance, therapy and advise on communication aids.

Dietitian: An expert in nutrition who works closely with speech and language therapists. They can help someone with MND maintain weight if swallowing becomes difficult.

Occupational therapist (OT): A therapist who helps people remain as independent as possible through equipment for daily living or mobility, adapting the home environment and informing people of different ways to do everyday activities.

Physiotherapist: A therapist who can offer guidance on managing fatigue, cramps and stiffness in muscles and joints. They can advise someone with MND about suitable exercise and, where necessary, advise you how to help with assisted or passive exercise. Exercise cannot reverse damage to muscle groups weakened by MND, but can strengthen muscles not yet affected and help improve or maintain range of movement in joints. Physiotherapists can also advise on ways to prevent or manage falls.

See Information sheet 6A: *Physiotherapy*.

Palliative care specialists: These teams work to improve quality of life for people with life-shortening conditions. They provide a wide range of support, including symptom control and guidance on psychological, social, spiritual and practical needs.

Respiratory team: This may include a respiratory consultant and a specialist physiotherapist who are experts in breathing. They can assess the needs of the person with MND and offer guidance on therapy and treatment, including ventilation (mechanical breathing support).

Counselling and psychology services: A GP can refer the person with MND to an appropriate service, counsellor or neuro-psychologist for emotional and psychological support. This may be particularly important if the person experiences changes to thinking and behaviour with MND. There may be a waiting list, but a local hospice, palliative care team or social worker may also offer counselling as part of their palliative support.

Pharmacist: A professional who dispenses prescribed medicines. They can advise on the best types of medication in particular circumstances, including liquid medication for ease of swallowing.

Complementary therapists: These therapists can offer a variety of complementary therapies, such as massage, acupuncture, reflexology and others. These do not replace conventional medicine, but work alongside it. Some people find these therapies ease symptoms and reduce feelings of stress or anxiety.

Wheelchair services: These professionals can assess seating needs and help arrange wheelchair supply, as appropriate. There may be waiting lists for NHS provision.

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

Social worker or care manager: Working for adult social care services, these professionals provide information, needs assessments for people with MND and carers' assessments. They provide guidance on care services, including home help or advice on residential and nursing care homes.

Benefits advisers: An adviser who helps with benefits queries and claims for financial support. They do not work closely with other members of the health and social care team, but on occasion may need to ask members of the wider team for medical evidence to support a claim. You can also search for government online information at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

MND Association regional care staff: Professionals who work for the MND Association across England, Wales and Northern Ireland. They work closely with local service providers to ensure care and support are available at the right time.

MND Association visitor (AV): One of our voluntary visitors, who provide free and confidential support to people living with MND, their carers, their family and close friends.

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

Your GP and community health team

Based within a GP surgery or local clinic, this community team includes GPs and district or community nurses. It may also include specialists such as speech and language therapists, dietitians, occupational therapists and physiotherapists.

See the earlier heading *Who is involved?* for a list of professionals and what they do.

How can they help?

Depending on their expertise, they can offer help with:

- referrals to other health and social care professionals or services
- managing and monitoring symptoms
- prevention of health problems and health checks (important for you as well as the person you support)
- accessing specialist equipment
- carer support, information and training
- prescribing of medicines (if authorised to do so).

See the heading, *Breathing support in Section 2: What to expect*, for details about GPs prescribing medicines for our MND Just in Case Kit.

How do we access this help?

Contact your local GP surgery to register as a carer. This places a flag against your record and helps the professionals involved to remain aware of your needs as a carer. If the person you support attends a different surgery, ask if you can register as their carer at this surgery too.

As MND progresses, the person with MND may be able to get support and symptom monitoring through home visits, by a district or community nurse, and other professionals as appropriate.

Most surgeries operate an out-of-hours service during evenings and weekends.

Do we have to pay for this?

The majority of NHS services are free, but exceptions may include:

- some dental and optical services
- larger items of equipment and assistive aids (the person with MND may be financially assessed to see if they need to contribute)
- some prescription fees in England, although the person with MND usually qualifies for exemption (prescriptions are free in Wales and Northern Ireland).

See Information sheet 10A: *Benefits and entitlements* for details about prescription exemption and costs for sight tests and dental treatment.

Specialist healthcare for MND

Specialist healthcare professionals can be based at the same location or as a virtual team in different settings. Some may make home visits, but this is not always possible.

See earlier heading *Who is involved?* for a list of professionals and what they do.

How can they help?

Specialists assess and monitor symptoms like the community healthcare team, but focus on provision of treatment for a particular area, such as breathing support.

As the carer, this can help you:

- plan ahead when symptoms first begin to show
- become more aware of interventions the person with MND does or does not want
- find out how to manage treatment, therapy or equipment within your daily routines.

“I would like more support to talk about the future and plan what can be done to help.”

In many regions, you may be able to get help from a co-ordinator who specialises in MND and can act as a main contact between specialists. They usually work for an MND care centre or network, but this role sometimes exists through other neurological clinics, palliative care services and hospices. GPs and neurological consultants can advise on MND co-ordinators in your area.

How do we access this help?

GPs or other health and social care professionals can refer the person with MND, and yourself, to specialists as needed.

Do we have to pay for this?

This type of NHS care is free.

MND care centres and networks

The MND Association part-funds a national partnership programme of MND care centres and networks across England, Wales and Northern Ireland. These are dedicated MND clinics where health and social care professionals come together to improve the standard of care for people living with MND. They also give guidance to carers.

How can they help?

Each team of specialist professionals (known as a multidisciplinary team) works in a co-ordinated way. They monitor and advise on symptoms and provide support and information. They do not replace the existing health and social care team for the person with MND, but work with them.

See earlier heading *Who is involved?* for a list of professionals and what they do.

It is important to note that most neurology clinics offer co-ordinated care and services for MND. The MND Association works in partnership with neurology and community services, as well as MND care centres and networks. Our aim is to improve services and help people with or affected by MND receive equal care at the highest possible standard.

See Information sheet 3A: *MND care centres and networks*, for more detail about these services.

How do we access this help?

If the person with MND wishes to access an MND care centre or network, they will need to ask their GP or neurological consultant for a referral. The service focuses on the needs of the person with MND, but you can attend appointments with them, which can help you feel more informed.

MND care centres are not purpose-built buildings. Appointments usually take place in a hospital or hospice. In most cases you need to travel to these appointments, but some teams may provide an outreach service, as do MND network services.

Do we have to pay for this?

Support from MND care centres and networks is free.

Adult social care services

These services usually include social workers, care managers, care co-ordinators and occupational therapists.

See the earlier heading *Who is involved?* for a list of professionals and what they do.

How can they help?

They can offer assistance through:

- a needs assessment for the person with MND to agree and arrange appropriate services, such as a care worker, or a personal budget to assist their needs
- a carer's assessment for yourself to agree and arrange appropriate services or a personal budget to assist your needs
- provision of small items of equipment
- advice on larger equipment, home adaptations and potential funding
- guidance on other services, benefits and emergency support
- psychological and family support

- guidance on selecting and arranging residential or nursing home care, should this be required, or working with healthcare professionals to provide care at home.

How do we access this help?

Contact adult social care services through your local authority or, in Northern Ireland, through your local health and social care trust. Sometimes, social care professionals work at a GP surgery, alongside the local community healthcare team.

Do we have to pay for this?

Some equipment may be free, but you may have to pay towards services. Income and savings will be considered to work out how much you may need to pay. In Northern Ireland, home care services are free, but you may have to pay for other help.

See Section 4: Carer's assessment for more detail about financial assessment and how services can be arranged, including direct payments to purchase services of your choice.

Specialist palliative care

Based in a hospital, hospice, day hospice or local clinic, specialist palliative care is provided by a team of health and social care professionals with training and expertise in support for life-shortening illness. Services can also be provided by home visit or in a residential or nursing care home.

“We have a good relationship with our local hospice...I keep telling people how good it is for living as well as end of life.”

How can they help?

This care looks at the person's needs as a whole. It includes symptom management, but also psychological, social, spiritual and practical support as required. The care given can range from clinical care and counselling, to complementary therapies and guidance on financial support. Carers and family members are also supported.

How do we access this help?

GPs and other health and social care professionals can refer the person with MND and yourself to specialist palliative care. Ask for early referral as soon as you both feel ready.

You may have to wait if services are busy in your area, but early referral enables you to build a relationship with a hospice or specialist palliative care team. This can bring added benefit as these services focus on quality of life. It also helps professionals to understand everyone's needs, wishes and preferences. If the person with MND has to be admitted to hospital for any reason, detailed knowledge about their needs may result in a shorter stay.

Do we have to pay for this?

Palliative care is usually free. These services are sometimes funded by the NHS, but also by charity funding (as with independent hospices). You may be charged for some services, such as complementary therapies.

Respite care

Short-term alternative care that allows you to take a break or regular breaks, is known as respite care. Although this support can be provided by family and friends, there may come a time when you need to involve professional help.

See Section 8: Looking after yourself for more about the benefits of respite and how to manage if the person you support does not want to receive this type of care.

Where services allow, respite care can be provided at:

- home
- a residential or nursing care home
- a day care centre
- a hospital
- a hospice.

How can they help?

In most cases, respite means that someone will sit with the person and support them for short, regular breaks. This could help you to go shopping, attend a course, make an appointment or visit family and friends.

“We receive help from the local hospice for three hours a week, and weekly day care there.”

Longer periods of respite can also be arranged so you can rest, take a holiday or receive treatment, if needed. This may mean someone coming into the home to provide care, or if care is complex or needed around the clock, the person with MND may be able to stay in a residential or nursing home for a week or two.

How do we access this help?

We recommend looking at options in advance, as respite care is not easy to arrange at short notice. You may also need to identify suitable support for MND, as professional carers may not have previous experience of working with the disease.

“My husband went into a care home for a week’s respite care at short notice and the care home was unprepared for dealing with his requirements and need for speedy attention.”

With MND, needs can change over time and become more complex, so you may want to keep a variety of contact details to hand.

The first step is to contact adult social care services through your local authority or, in Northern Ireland, through your local health and social care trust. They can arrange an assessment for the person you support to work out their needs and a carer’s assessment for yourself. You can ask for advice about respite providers at the assessment.

See Section 4: *Carer’s assessment for details and our write-on forms at the end of this guide for tracking contacts.*

Local carer centres and hospices can direct to specialist respite providers, but may not be able to recommend one service above another.

If the person did not require respite care before, but their needs have increased, this can be reviewed. They can have their needs assessed again, as can you, with a focus on respite and other support.

Adult social care services can also advise about out-of-hours support, for care cover in urgent or emergency situations. It is worth finding out contact details for this service and keeping these in or near your telephone.

See later heading, *Emergency and urgent support.*

Do we have to pay for this?

There is normally a charge for respite care, but you and the person you support may receive help towards this, depending on the outcome of your assessments.

If you seek respite care on your own, there will be a charge, but there may be local schemes to help with carer breaks. Ask about grants for carers during your own assessment, to find out what may be available and if this can be included in your care and support plan.

Residential and nursing homes

There may come a time when the person you support needs more care than you can realistically provide at home. Respite care can help for short periods of time, but if the situation is ongoing, residential or nursing care may need to be considered.

Even where every effort has been made to enable the person with MND to stay at home, this sometimes has to change.

“I know I won’t be able to do it all on my own soon. Right now there is no telling him that and I don’t know how to bridge the reality of his needs with my capability. It really worries me.”

This can be a difficult decision for you both, but it does not reflect on the care you provide. Residential nursing care may be necessary where:

- there is a need for complex medical care
- a hospital admission for urgent or emergency care results in ongoing nursing care
- your own ill-health means you become unable to continue providing support
- you have children or other dependants who also need your support
- you do not have a personal or family network to help
- changes to thinking and behaviour have caused the person with MND to become aggressive or a risk to themselves.

How can they help?

Both residential and nursing care homes provide accommodation, meals and personal care support, but nursing homes employ registered general nurses.

These nurses also work in a co-ordinated way with other healthcare professionals, to ensure medical needs are met.

Someone with MND is more likely to need nursing care, especially if their medical needs become complex and they need help with eating, drinking and breathing.

Some homes are dual registered, which means they can provide nursing care if needed.

How do we access this help?

Adult social care services can assess if the person with MND requires residential care. Contact your local authority or, in Northern Ireland, your local health and social care trust.

Where nursing care may be required, an NHS healthcare professional will also need to assist with the assessment.

This may be a good time to apply for NHS continuing healthcare. This is often provided in a nursing care home, but can sometimes enable a person to remain in their own home with nursing support.

See later heading, *NHS continuing healthcare.*

The person you support must agree to any care plans that are made. The only exception is where dementia or severe changes to thinking mean that the person is unable to make decisions on their own behalf. In this situation, a health or social care professional will need to assess their ability to make decisions (known as mental capacity). They will then work with you to make decisions based on the best interests of the person with MND.

“We are just looking into residential care, but it’s difficult to find a place as his needs are so complex.”

When selecting a care home, ask the following questions:

- Do they have the necessary experience with neurological conditions to provide suitable care for MND?
- How do they support needs such as speech and communication, mobility and help at mealtimes, including tube feeding if required?
- Can they support advance care planning and end of life plans?
- When are you allowed to visit?
- Are you allowed to help with care tasks if that is something you and the person with MND would like?

You can read inspection reports to see how a home is rated:

- for England, see the Care Quality Commission website at: www.cqc.org.uk
- for Wales, see the Care Inspectorate for Wales website at: <https://careinspectorate.wales>
- for Northern Ireland, see the Regulation and Quality Improvement Authority website at: www.rqia.org.uk

See also Section 12: *Useful organisations and www.mndassociation.org/mycare*

Do we have to pay for this?

In a nursing care home, registered nurses are usually employed by the care home itself, but the NHS makes a payment to the care home to fund this. If someone is paying for this care themselves, the fees should be reduced by the amount the NHS pay.

For residential care without NHS-funded nursing care, a financial assessment will be arranged to see if the person with MND needs help to pay or must pay for this themselves. Most people are expected to contribute towards care in a residential home, depending on capital and savings.

If the person qualifies for NHS continuing healthcare, all of their personal and medical care will be fully funded.

Emergency and urgent support

No matter how well you plan, or how much support you have in place, something unexpected may happen. We provide a *Motor neurone disease checklist* to help people think ahead.

See *Further information at the end of this section for details about how to order our publications.*

It is important to identify out-of-hours support and emergency services, so that you feel prepared.

How can they help?

Out-of-hours support and emergency services can provide:

- emergency care cover if you suddenly find yourself unable to support for any reason
- emergency medical care for the person with MND, if needed, (this may require hospital admission).

How do we access this help?

If you have a carer's assessment, ask about emergency care cover services. You can also contact your local authority at any time to find out more. In Northern Ireland, contact your local health and social care trust.

The GP and members of the health and social care team who support the person with MND can also advise about emergency and urgent support. The GP will usually add the person with MND to an electronic end of life register, which can help professionals remain aware of particular needs in emergency situations.

Keep all contact numbers for emergency assistance in or near your telephone. In urgent medical situations, call 999 for assistance.

Do we have to pay for this?

Emergency healthcare is free, however, there may be a charge for emergency care cover. Depending on the services arranged, some contribution may be required and the person with MND may be financially assessed, as part of their own needs assessment.

There are various ways to alert emergency teams about the needs of the person with MND. The following may help bring peace of mind in urgent situations:

Ways to raise an alert	What this provides
Carer emergency card	A card to carry in case you are involved in an emergency and unable to communicate. Usually linked to a registration service, the card alerts authorities that you are a carer and means the person you support will receive help. Ask your local authority if they have a carer card scheme, or your local health and social care trust in Northern Ireland.
Message in a bottle	A sticker on the fridge and inside of the front door where the person with MND lives, tells paramedics an alert bottle can be found in the fridge. This can contain essential personal and medical details. Bottles are free of charge from your local chemist. You can find details through the Lions Club. Search for <i>message in a bottle</i> at: https://lionsclubs.co
MND Alert Card	We provide this small card for the person with MND to carry in a purse, wallet or pocket. This helps to alert hospital staff that they need specialist help for MND, with space to record key contacts.
Understanding My Needs	We provide this write-on booklet to help someone with MND record their needs and personal background. This can help guide care workers, or hospital or hospice staff.
MedicAlert	This registered charity provides an identification system for individuals with medical conditions and allergies. Usually in the form of a bracelet or necklet, which you purchase, the scheme is supported by a 24-hour emergency telephone service. You can find details at: www.medicalert.org.uk
MND Association Just in Case Kit	A box designed to hold medication to relieve sudden breathlessness and anxiety. This can be ordered from the MND Association by a GP, who will prescribe suitable medication and discuss usage with the person and yourself, as their carer. The box is kept at home 'just in case'.

Ways to raise an alert	What this provides
Important care documents	<p>If the person with MND has advance care plans, end of life care plans or an Advance Decision to Refuse Treatment (ADRT), ensure these documents are easy to find in an emergency. For example, it is not advisable to lock them away in a safe, which may be difficult to access when needed. Paramedics and medical teams need to be able to see these documents if they are to respect the wishes of the individual. If you use the Message in a bottle scheme, the bottle may not be big enough to hold all these documents, but you could add a note of where to locate them to raise awareness.</p>
Telecare and telehealth	<p>When the person with MND is being assessed for their care needs, ask about equipment to send messages to a health monitoring service. If you cannot be with the person at all times, this can ensure assistance in case of a fall or other urgent situation. There may be a charge for this.</p>

Care following a hospital stay

If the person you support has been admitted to hospital for symptom control or urgent care, both their needs and yours should be assessed before discharge. A care plan should then be provided, usually by adult social care services. Many hospitals have dedicated discharge teams who do this.

How can they help?

Where an increased level of care will be required as a result of the treatment, services should be arranged promptly to help you in your care tasks.

How do we access this help?

If the person you support is going to be discharged and you have not been approached about a care plan, you have the right to ask when it will be carried out. Feel confident about making this request, as care plans are a requirement for the hospital and adult social care services. It is important that you both receive adequate support.

Do we have to pay for this?

Depending on the services arranged, some contribution may be required and the person with MND and yourself may be financially assessed, as for a needs or carer's assessment. However, there are no charges for medical care.

NHS continuing healthcare

If the needs of the person with MND become complex and require medical help, they may be eligible for NHS continuing healthcare. This funds and organises appropriate care and support, which can relieve pressure on you as the carer.

In Northern Ireland there is no guidance on NHS continuing healthcare, but health and social care trusts are encouraged to provide this support and follow the criteria used by the rest of the UK.

See Information sheet 10D: *NHS continuing healthcare* for details about the assessment required for this service.

How can they help?

If the person with MND qualifies, all of their care needs will be met by professional care support (whether personal or medical). The care package is sometimes provided at home, but may need to take place in a nursing care home if the person's needs are very complex.

How do I access this help?

The person with MND must require a high level of healthcare and support to qualify. If their symptoms are progressing rapidly or they need end of life care, they are more likely to receive NHS continuing healthcare. They may also qualify for 'fast tracking' which can speed up the application process.

Ask any member of the health and social care team for guidance about referral for NHS continuing healthcare. A team of professionals will be involved in the assessment process and as the main carer, you should be consulted.

Do we have to pay for this?

If the person with MND qualifies for this type of care, it will be funded entirely by the NHS. In some cases, a 'shared care package' may be provided between the NHS and adult social care services.

Support from other organisations

A variety of local, regional or national organisations may be able to offer guidance, information, support or funding to you and the person with MND.

See Section 12: *Useful organisations for suggested services and contact details.*

Support from the MND Association

We offer a range of support for people with MND, their carers, families and the professionals who provide care.

See Section 11: *How the MND Association can help you.*

Support from people affected by MND

You may wish to seek support from others affected by MND. Our branches and groups offer the chance for get-togethers and often host meetings specifically for carers. If this does not feel appropriate for you now, it may be useful in the future.

"I would like a carers' group so I could share experience, as we are very rural and there aren't many carers nearby."

You may also find our online forum useful at: <https://forum.mndassociation.org> which provides a safe place to share experiences with others affected by MND.

"I regularly read the problems and comments on the forum and find these very helpful, although I have never joined in or posted anything myself."

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

Key points

- Find out about out-of-hours and emergency support as soon as you can – it is always better to be prepared. Having this information to hand can bring peace of mind.
- If you need to, ask questions when supporting the person with MND at appointments. You need guidance too.
- The health and social care team supporting the person with MND should include you in discussions about care arrangements, where this affects you and the support you provide.
- You can note questions to ask at appointments and answers given using our *Appointment queries* form at the end of this guide.

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:

3A: MND care centres and networks

6A: Physiotherapy

6B: Complementary therapies

From our other publications:

MND Alert Card: a small card for the person with MND to carry in a purse, wallet or pocket. This helps to alert hospital staff that they need specialist help for MND, with space to record key contacts.

Understanding My Needs: a write-on booklet to help someone with MND record their needs and personal background. This can help guide care workers, or hospital or hospice staff.

Motor neurone disease checklist: to help someone with MND think about their wellbeing and the support they may need.

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.

Personal care: our booklet about managing daily routines.

Emotional and psychological support: our booklet about available therapies.

Changes to thinking and behaviour with MND: our booklet on how to seek support if these changes are experienced by the person with MND.

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

6: Work and financial support



This section can help you think about how to juggle work and care, or seek financial support.

If you are employed and supporting someone with MND, you may be faced with some challenging decisions, such as:

- Can I continue working while caring?
- How do I access help to continue my work?
- How will I cope financially if I leave work to become a full-time carer?

It can be a confusing time. When a partner, relative or close friend is diagnosed with MND, it changes everything for them. If you find yourself taking on the role of carer, your life changes too. This can include your work.

Whether working or not, you may also find that finances are stretched. MND is a demanding disease and it can help to understand how to access financial support if needed. Especially if you become a full-time carer.

“I work, but I’m concerned about the future. We’re spending a lot of money on adapting our house, but I worry how long we can afford to stay here.”

See our information sheets 10A to 10F, for a range of guidance about financial support and social care.

Can I juggle work and care?

Being a carer and trying to keep up with your working life can be difficult, with many pressures. Decisions about whether to continue work or not can affect your:

- sense of identity
- sense of purpose
- standard of living
- social network
- daily routines
- approach to financial support.

Getting help is not always easy, but it helps to know who to ask. You may find it helpful to discuss your concerns with:

- your employer
- adult social care services
- your local job centre (about benefits)
- the person you support
- family and friends
- someone at a local carer centre.

You can also contact our MND Connect helpline, who can provide guidance and direct you to our regional services, branches and groups. There may be an Association visitor in your area who can support you through these decisions, by phone, email or home visit.

See Section 11: *How the MND Association can help you* for contact details and further information.

See also later heading in this section: *What if I am self-employed?*

What options do I have?

When making decisions about work, care and financial support, you may wish to consider the following:

- flexible working hours
- sharing care with family and friends
- a needs assessment for the person you support and a carer's assessment for yourself (which may lead to help from care services, care workers and financial support through direct payments or benefits)

See Section 4: *Carer's assessment.*

- adapting the home and using assistive equipment to help the person with MND remain independent for as long as possible
- day care centres
- leaving work to become a full-time carer
- voluntary redundancy if available
- early retirement (take advice, as this may affect other financial support, such as benefits)
- residential or nursing care for the person you support (this may not feel acceptable at first, but could become an option if the person's needs become complex and frequent medical interventions are needed).

Respite care for short regular breaks or longer breaks to take a holiday can also be helpful. If the person with MND has complex needs, they may need specialist care from care workers experienced with MND.

See Section 5: *What kind of support is available? for more about respite and nursing care.*

What is flexible working?

This is a way of working to suit your needs, such as:

- flexible start and finish times
- working from home
- job sharing

- working your agreed hours over fewer days (compressed working)
- part-time work
- your hours worked flexibly over a year (annualised hours).

You can find out more for England and Wales at: www.gov.uk/flexible-working or for Northern Ireland at: www.nidirect.gov.uk/flexible-working

It is everyone's right to make a request for flexible working, but you must have worked continuously for your employer for at least 26 weeks to apply.

Your employer can refuse a request if they have a good business reason for doing so, but you can appeal. This is usually done through the grievance procedures of the employing body, but you may also find it helpful to contact your local Citizens Advice Bureau. You can find out your nearest branch through your telephone directory or online at: www.citizensadvice.org.uk

Can I ask for paid or unpaid leave?

There may be times when you need to provide more intensive care. This can happen if:

- the person you support needs more care until additional care support is in place
- there is a breakdown in any professional care support
- the person you support has an accident or unexpected illness
- the person needs treatment and there is a recovery period.

A period of leave may be the solution.

Arranging paid or unpaid leave is at the discretion of your employer. It is worth finding out if you can get carer leave or compassionate leave. This may be useful if you need emergency leave at short notice. It can be less stressful if you know how this works in advance of urgent situations.

If you are thinking about leaving work, also ask if your employer would consider a career break. This may enable you to return to work if your caring responsibilities change.

How do I manage relationships at work?

If you are juggling work and care, it can affect the way you communicate with your colleagues.

“Dealing with work colleagues who don’t have much idea what caring is all about can be tricky, as you often don’t have the energy to talk about things.”

You may find that you:

- have less tolerance when annoyed by something
- feel different to others and distanced in conversations
- don’t know how to answer questions about your situation because you feel protective of the person you support
- feel too tired to be sociable
- feel vulnerable and emotional.

These are all natural reactions and to be expected.

If your employer provides counselling services or carer support, you may find this helpful. Ask human resources for details.

If you have a trusted colleague at work, it may help to let them and your manager know how you are feeling, as they may be able to support.

What if I decide to leave work?

Combining work and caring is not easy. You may have days when leaving work feels like the only option. At other times, you may feel more than able to cope. For many carers, work provides more than income, it helps maintain a sense of self and connection with the wider world.

It is quite normal to feel up and down when caring, and to change your mind, so think carefully before making any decisions.

“I can spend time with my wife, even though the circumstances and things I need to do for her weren’t planned.”

Everyone’s situation is different, but it helps to consider how leaving work will affect you in terms of:

- independence and social interaction with colleagues
- finance
- employment skills
- pension entitlement
- qualification for benefits.

Leaving work will impact on your income, but you may become entitled to certain benefits, which can help.

See later heading: *Which benefits and entitlements are important to explore?*

We recommend asking an independent financial adviser and a benefits adviser about income, pensions and benefits.

See our sheet 10E: *Work and motor neurone disease for more details about options for continuing or leaving work.*

What if I am self-employed?

If you are self-employed in any capacity and making decisions about your future, seek advice from an independent financial adviser. It is important to review your income, tax liabilities and any financial investments.

You may also wish to see:

- a benefits adviser to review any benefits and entitlements that may be available to you
- a legal expert specialising in self-employment or company law if you have any contract or legal accountabilities.

Which benefits and entitlements are important to explore?

If you have never claimed benefits before, it may feel daunting to do so. However, it is your right to claim. If you qualify, the financial support may help bring peace of mind.

Some benefits are **means tested**, where you or the person you support will be financially assessed. This means your income and savings are taken into account to work out how much you are entitled to receive.

The following list highlights benefits and entitlements relevant to MND and caring. Some of these apply to the person you support, but are included here as any help they receive can also help you in your caring role.

These brief descriptions will help direct you to key benefits and we recommend exploring these to understand the qualifying criteria.

“Support is out there, but you have to know the system and fight for it.”

We provide detailed information to help with this:

See our sheet 10A: *Benefits and entitlements for more information and see contact details, who qualifies and how to claim.*

You can also find out more at:

www.gov.uk (England and Wales)
www.nidirect.gov.uk (Northern Ireland)
www.citizensadvice.org.uk

Attendance Allowance (AA):

For people of state pension age to help with extra costs if they have care needs. People with MND may be able to have their claim ‘fast tracked’, which can speed up the application process. Not means tested.

Carer’s Allowance:

For carers who provide care for 35 hours or more a week to support someone receiving AA, DLA or PIP. Not means tested, but income and some benefits may affect whether you qualify.

Carer’s Credit:

If you are of working age and your caring role creates gaps in your work history, this credit protects your National Insurance.

Carer’s Premium:

If you can’t get Carer’s Allowance because you are being paid another benefit that overlaps with it, you can still get an extra amount known as the Carer’s Premium if you meet all the criteria for Carer’s Allowance. You must still make a claim for Carer’s Allowance to qualify.

Council tax support:

You may qualify for support with council tax in England and Wales. As with all the entries here, see information sheet 10A - *Benefits and entitlements* for more details.

Disability Living Allowance (DLA):

This used to be the main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. New claims now have to be made for the replacement benefit called Personal Independence Payment (PIP). Anyone under 65 who is already claiming DLA will be contacted at some point to let them know when their DLA will end and to make a new claim for PIP (see Personal Independence Payment in this list). Anyone born on or before 8 April 1948 can retain their DLA award if they still qualify. Not means tested.

Disabled Facilities Grant (DFG):

A local authority grant to help towards the cost of adaptations or installations at home, to enable someone with disabilities to continue living there. A DFG can take a long time to agree and arrange, so it is important to plan ahead rather than waiting until point of need. DFGs are means tested.

Pension Credit:

This is sometimes referred to as State Pension Credit. This is for people of state pension age and there are two parts: the Guarantee Credit, designed to top-up your income to a guaranteed minimum level and Savings Credit to help those who have made some retirement provision in addition to their state pension. Depending on your circumstances, you may get one or both of these elements.

Personal Independence Payment (PIP):

The main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. This is replacing Disabled Living Allowance (DLA) –see earlier in list. People over 65 can claim AA instead (see Attendance Allowance). People with MND may be able to have their claim ‘fast tracked’, which can speed up the application process. PIP is not means tested.

Rate Relief:

If you receive Housing Benefit in Northern Ireland, you may qualify for Rate Relief.

Social Fund and emergency loans:

For people on a low income to help with certain one-off or occasional expenses, such as budgeting loans. These are means tested.

Universal Credit:

For people on a low income whether working or not. This new benefit has replaced six other benefits:

- Jobseeker’s Allowance
- Housing Benefit
- Working Tax Credit
- Child Tax Credit
- Employment and Support Allowance
- Income Support

Benefits Advice Service:

The MND Association Benefits Advice Service provides free, confidential and impartial guidance on any benefits you may be entitled to receive.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: through the website contact page at:
www.mndassociation.org/benefitsadvice

What is NHS continuing healthcare?

This care is provided by the NHS when someone has complex physical or mental health needs, resulting from disability, accident or illness.

See also NHS continuing healthcare in Section 5: *What kind of support is available?*

The care covers all needs, including health and personal care. It is either fully funded by the NHS or part of a shared care package between the NHS and adult social care services. This care can take place in a range of settings, including the person's home, nursing home or a hospice.

In the later stages of MND, care needs increase and you may find this overwhelming to manage alone. Although NHS continuing healthcare is not usually provided for MND in the early stages, it may be agreed if needs become complex and require frequent medical intervention. It is worth finding out about NHS continuing healthcare and how the application process works, so that you feel prepared in case it is needed.

See our sheet 10D: *NHS continuing healthcare for more information and how to apply.*

In England and Wales, NHS continuing healthcare follows similar rules, but there may be some differences in the systems used.

In Northern Ireland there is no guidance on NHS continuing healthcare. We recommend contacting your local health and social care trust for advice if care needs become complex.

Key points

- If you work, ask your employer about flexibility at work and how to take leave in urgent situations.
- Take advice from a wide range of people and advisers before making any decision that will affect your income or potential future benefits.
- Don't be afraid to claim benefits if needed, this is your right. Try to explore areas of financial support as early as possible to be aware of how to access help.
- Contact your local carer's centre or group who may be able to advise about support and services in your area.
- You can find out a great deal about social care support and financial support through a needs assessment for the person you support and a carer's assessment for yourself.

See [Section 4: Carer's assessment](#).

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:

10A to 10G:

our range of sheets on benefits, financial support and social care

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.

Getting around: our booklet on driving, transport and holidays.

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

If you have any further questions about benefits for yourself or the person you support with MND, contact our:

Benefits Advice Service:

The MND Association Benefits Advice Service provides free, confidential and impartial guidance on any benefits you may be entitled to receive.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: through the website contact page at:
www.mndassociation.org/benefitsadvice



Part 2: Emotional and personal support

Section 7: Making sense of your feelings

Section 8: Looking after yourself

Section 9: Support for children and young people

Section 10: Beyond the caring role

7: Making sense of your feelings



This section explores the feelings, emotions and reactions you may experience when supporting a partner, relative or friend living with MND.

Supporting someone with MND can sometimes feel emotionally overwhelming. Understanding some of the reactions you may experience can help you to recognise these feelings as they appear. This can help you manage your emotions, so you feel more in control.

Whatever mix of emotions you feel, these are natural responses to a very challenging situation. If there are times when you feel you have reached your limit, remember that MND makes huge demands of carers and then keeps demanding more. Strong feelings are to be expected.

Your background, beliefs and the unpredictable nature of MND mean that no-one else can truly understand how it makes you feel. However, you are not alone.

Others affected by MND, and the professionals who provide support, know how challenging MND can be. They can offer practical solutions to help you achieve the best possible quality of life in these circumstances. If you experience persistent difficult emotions, ask your GP for advice – they can refer you to specialist help if needed. Even if you don't wish to talk to anyone else at the moment, it may help in the future.

You can ask our MND Connect helpline about ways to connect with others. They can provide details about our Association visitors, branches and groups, regional staff and other organisations who provide support for carers. The helpline team can also offer support by phone or email:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

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

What can I expect?

Your experience will be unique, but you are likely to feel many different emotions. You may feel more than one emotion at a time, such as anger and guilt. This can be confusing.

Dealing with the shock of diagnosis is the first hurdle. Life has suddenly changed. You may need time to adjust and process all of the information you have been given.

Relationships may change too. Feelings of love for the person with MND can strengthen following diagnosis, yet this will be mixed with sadness. However, if the relationship was difficult before MND, this may worsen during the challenges ahead. If the person develops problems with speech and communication, you may feel a sense of becoming 'distanced' from them, regardless of whether the relationship is positive or not.

“Resentment began to replace the compassionate feelings I used to have. If communication is affected, it's more difficult to have the discussions that would put this right.”

As a carer, conflict can be hard to deal with, especially when you are tired and have increasing responsibilities. Some support may also feel more intimate than you expected, such as personal care and helping someone to wash, dress or go to the toilet. The supporting health and social care team may be able to advise and suggest ways to help. The team can also help to facilitate sensitive family discussions about current and future care.

The person with MND is likely to feel strong emotions too. They may even show signs of changes to thinking and behaviour, and you may feel they are no longer interested in you. If you were previously close, this can be upsetting, but it helps to understand that this is part of the disease for some people with MND. If you suspect this is happening, we can provide information to help.

*See our booklets **Emotional and psychological support** and **Changes to thinking and behaviour with MND**.*

With caring, there can be many positive emotions. You may feel great satisfaction at times, perhaps when you and the person you support have faced a challenge together.

At other times, you may feel more difficult emotions. These can be felt by the person with MND too, but not necessarily at the same time as yourself, which can make it harder to cope with your feelings.

Challenging emotions might include:

- denial
- anger
- resentment
- guilt
- frustration
- anxiety and fear
- loneliness
- sadness
- helplessness

You may not experience all of these emotions. Some may happen once, others may come and go. You may have other feelings not listed here, but emotion is simply a natural reaction to change and challenge.

It can help to remember that difficult emotions may reflect something positive. For example:

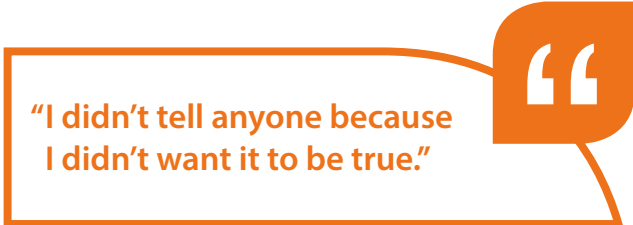
- sadness can reflect the depth of feeling you feel for someone
- guilt indicates that you care about what is happening around you
- anger can be a healthy response that enables positive action.

However, if these emotions become overwhelming, they may be difficult to manage. This section focuses on difficult emotions to help you look after your own wellbeing. Developing ways to cope with your feelings can help you reduce stress levels and feel better prepared for what lies ahead.

Denial

During the shock of diagnosis, there can be a sense of disbelief. 'This can't be happening. They must have made a mistake.' To feel this way is understandable. No-one wants to hear such news.

Most people have an expectation of what life will be like in the future and have long-term plans. A diagnosis of MND changes everything and sometimes denial feels like the only option. You may feel as though acceptance is 'giving in' to the disease.



"I didn't tell anyone because I didn't want it to be true."

Denial can also result from not wanting to upset the person with MND, or other family members and friends.

However, over time, denial may make it more difficult to cope with the challenges of MND, as symptoms can progress rapidly.

Most people find it helps to plan ahead and think about future needs. Waiting until point of need may make problems harder to manage, as support and equipment can take time to source and arrange.

If you can acknowledge and accept what is happening, you may find you are better placed to seek information and support.

How do I manage this?

Sometimes, when we try hard to avoid something, it bothers us even more, which can lead to anxiety and stress. By facing challenges, you are more likely to adjust and become more resourceful. Accepting someone has MND does not mean giving up.

Letting go of things beyond your control may help you deal better with things that can be managed. This is not easy to do, but support from health and social care professionals can help. Try not to dwell on 'why?' and 'what if?'. You may not be able to change the future, but planning ahead can help you regain a sense of control and purpose.

Having open conversations with those around you can help break down barriers about acknowledging the disease. If possible, this is important to do with the person you support. You need to work together as a team and both of you need to understand each other's needs in this situation.

"Everyone needs to face what's happening together to feel prepared and supported."

Wider conversations with family, friends and health and social care professionals can also help. These may be emotional discussions, but that is to be expected. If you get upset, this may give others permission to release their feelings too. This can help everyone around you to accept what is happening and begin to manage the impact.

Anger

Anger is a very common reaction for anyone in a caring role and particularly when someone is diagnosed with a life-shortening condition. You may ask yourself why this is happening to the person you support, and to yourself. This is understandable, but there is no answer to that question.

No-one did anything wrong. It isn't your fault or the fault of the person with MND.

This does not mean you shouldn't be angry. Anger is a natural reaction to unwanted change and can help you to feel stronger. At best, anger can empower, but at worst it can feel damaging and may not achieve the best results.

"I'm concerned that I become short-tempered when I am tired."

Anger can be caused by many things. When facing the demands of MND, you may feel angry because:

- you never have time to rest
- you have to watch someone you love become increasingly unwell
- future plans and dreams have to change
- MND affects quality of life for you and the person you support
- doctors should be able to make the person with MND better
- you have no outlet for your anger (or you may take it out on family and friends)
- people offer advice when they have no idea what caring and MND is like
- other people still have their health and can do what they like.

If you can identify the cause of your anger, it is easier to deal with and may help to reduce the intensity of the feeling.

How do I manage this?

As you get better at identifying anger, learn to take a break from whatever is causing the feeling to build. Where possible, do something else until you feel more in control.

This does not mean you should 'bottle-up' things that make you repeatedly angry. Let others know how you feel, rather than keeping anger inside. This helps them know when to give support or adapt their own approach.

Think about what has gone well. Acknowledge when you are succeeding, even in the smallest things. It may be difficult at first, but learn to appreciate your own abilities. You may be learning as you go in the caring role, so recognise how your skills are growing and take confidence in this.

It is okay to laugh. No matter how difficult life may feel, there are still times when you need to laugh and it can help to diffuse anger.

Resentment

Resentment is similar to anger, but feels intensely personal. It is easy to feel this as a carer. You have to provide increasing levels of care, while the person you support becomes less able and more dependent (especially if they experience any changes to thinking and behaviour). You may feel there is no 'you' anymore and that you have ceased to exist as a person in your own right.

"I feel stripped of every human right as I am just the carer, while everyone fusses around him."

If you live with the person you support, you may feel as though your home has been invaded too. Equipment, installations and even changes to layout may be necessary.

As the disease progresses, you may also have more visits from health and social care professionals, or find you have to organise your time around appointments for the person with MND.

"With care workers coming in, your home is not your own... and we've had so many alterations. Everything is geared to the person who is disabled."

Resentment can build when:

- the person can no longer do things they have always done
- tasks make you uncomfortable, such as intimate personal care
- you have to take on more household tasks with no time for things you enjoy
- wider family and friends are not offering support as hoped, or you see them living with freedom of choice.

Feeling resentment can lead to other emotions, such as guilt. However, keep in mind how much you do and accept that these feelings are to be expected from time to time. The person with MND is being cared for, but all too often there is not the same level of support for the carer.

How do I manage this?

You must tell the health and social team who support the person with MND when you need support too. They may not realise when you are under pressure or assume you already have support in place.

Ask for a needs assessment for the person with MND and a carer's assessment for yourself. There may be services or respite care that can help.

If you have been assessed, but needs have changed, ask for a review.

See Section 4: Carer's assessment.

“Extra care was provided so I could take three to four hours off to go for a meal with friends.”

Taking a break does not mean you are letting down the person you support. It means you are looking after your own wellbeing, so you can continue to provide support if this is what you wish. Care workers often have long shifts, but then leave work and rest. As an unpaid carer, you are constantly on call. You may have to seek support to allow you to rest too, or just to get things done outside of the home.

See Section 8: *Looking after yourself.*

Family and friends may not realise how they can help, so let them know. Rather than asking for help in general, keep a list of tasks handy to give to people. You may be surprised at how willing they are to help. Things like shopping, laundry and cooking meals can make a real difference on days when everything else feels overwhelming.

Guilt

Balancing a caring role with everything else in life is not easy. You may feel guilty because:

- the other person is ill and you are not
- you worry whether you are a good carer or not
- you never seem to be able to get everything done, no matter how hard you work
- you sometimes get irritated with the person you support
- you would rather not be a carer
- your children or other people need you and there is too little time for everyone.

“I feel stretched all the time and guilty that I cannot be both a carer and the best mother I can be.”

See Section 9: *Support for children and young people* for information about children and young people affected by MND in the family.

How do I manage this?

As a carer you may be determined not to complain, thinking, ‘I’m not the one who is ill.’ Or you may be convinced that you could do more.

“If you do make some time for yourself, you feel you should not be doing so.”

However, the way you think about the situation is not necessarily how others feel. Those who are close to you, including the person with MND may:

- not realise the pressure you are under because you seem to be coping so well
- think you are achieving the impossible and feel very proud of you (and you may need to hear this)
- need to consider how to help or work with you in ways that are more supportive
- be able to listen and encourage, which can help you feel that someone understands.

Being open and talking about your feelings can help everyone else to help you.

Be honest with yourself too. Sit down and think about all the things you do. Realising how much you give can help balance any feelings of guilt. You may find it helps to write down the tasks you do and how long these take. You may think, ‘I don’t have time for that’ but as well as acknowledging what you are achieving, this can provide useful evidence at a carer’s assessment. Good evidence about the impact of caring tasks on your time may help you get more effective support.

See our *Care summary* form in Part 4 of this guide, which can help you track how much care you provide.

There is nothing you could have done to prevent the disease, or the difficulties it creates. Learning to accept this may help reduce feelings of guilt.

It may help to think about yourself with compassion, as well as the person with MND. You are in this together and MND affects both of your lives. This can help balance any sense of self-criticism, which is easy to do as a carer.

Frustration

We can all get frustrated waiting for something we need and this can be an issue with MND. Equipment and services can take time to arrange. There may be waiting lists for some areas and in the meantime, the person with MND may find their symptoms progress. If needs change, support may no longer be suitable when it arrives.

With MND, ordinary tasks can also take longer to achieve, for you and the person you support. This requires patience, but if you are already tired, it becomes more difficult to remain tolerant.

How do I manage this?

Planning ahead is important with MND, as symptoms progress quickly for some people. Being well-informed can help and we provide a wide range of information on the disease, its symptoms and management. You can find out more about our publications at the end of each section in this guide.

See also Section 2: *What to expect.*

Knowing what could happen is a first step. Having open conversations with the person you support is also important to understand their wishes about future treatment and care. You can then access appropriate help as early as possible, when symptoms first begin to show.

Often, the timing of interventions is important, as certain treatments may carry more risk if they are introduced later in the course of the disease.

Being able to put support in place at the right time can prevent frustration building and help avoid urgent situations.

However, no matter how much you try to plan, MND is unpredictable and can catch you out. The daily challenges can also be frustrating in themselves. Dealing with frustration may be inevitable, but the more informed you become, the more you can reduce the risk of it happening.

See *Further information* at the end of this section for details about our publications and helpline.

Anxiety and fear

When someone is diagnosed with a life-shortening illness, anxiety and fear can become overwhelming. Fears can be wide-ranging, but you may worry about:

- the unknown and what will happen next
- not being able to cope
- how the person with MND will cope if you cannot be with them
- how the person with MND will die
- what the future will be like without them.

With the unpredictable nature of MND, it can feel as though control has been taken away. This can leave you feeling very vulnerable.

How do I manage this?

Finding out the facts and knowing what to expect can reduce fear. When we imagine what is likely to happen, it is often far worse than reality. Media stories about MND can also frighten and may not always present a balanced view.

The health and social care team supporting the person with MND can help put your mind at rest by discussing concerns. While there is no cure for MND, much can be done to help the person feel comfortable.

See Section 2: *What to expect.*

“I would like more emotional support, perhaps involving all the family. I feel there is a tendency to try and ignore, or not deal with, the emotional impact of caring for a loved one with MND.”

Anxiety and fear are likely emotions, but rarely constant. If they do persist and start to affect daily life, you may need support. Talk to your own GP, who may either refer you to counselling or the person with MND to a hospice or specialist palliative care (where supportive discussions include carers and family too). There may be waiting lists, but do ask if you feel this might help. Your GP may be able to advise on other ways to seek appropriate support.

Hospices and specialist palliative care teams offer a wide range of services for people with or affected by life-shortening illnesses to help them achieve the best possible quality of life. A referral does not necessarily mean the person with MND is in the final stages and this care should not be confused with end of life care.

See Section 5: What kind of support is available?

In most cases, palliative care does not require an overnight stay in a hospital or hospice, and may even be delivered at home or at a day centre. This can include support such as complementary therapies, which help some people to ease anxiety and stress.

“We have a good relationship with our local hospice...it’s an uplifting experience.”

Complementary therapies are usually made available to carers as well as the person with MND. There may be a charge, but some therapists offer voluntary services through hospices. This type of therapy can feel as though someone is ‘caring’ for you too and may help you feel more able to cope.

As a carer, it is never easy to find time for you, but there may be a possibility of arranging a joint appointment for you and the person with MND so that you can relax and enjoy the therapy.

Loneliness

You may feel at times that you are facing the caring role alone and that no-one else understands.

Caring for someone is demanding. You may find:

- it leaves you with no time of your own and socialising becomes difficult
- you decide to leave work as the level of care increases, losing contact with colleagues
- family and friends pull away and you see less of them.

Family and friends sometimes find the nature of MND difficult to deal with. They may even stop visiting altogether, which can feel very isolating. If you are tired and emotionally drained, you may feel withdrawn even when you are in other people’s company.

As MND can affect speech and communication, the way you interact with the person you support can also change.

“His speech is already slurred and faint, and he is understandably unwilling to speak unnecessarily. I find this very upsetting and feel very isolated.”

How do I manage this?

Keeping communication open with the person you support is important for you both. If their speech or ability to gesture become affected, ask their health and social care team for a referral to a speech and language therapist (SLT). It is helpful if the SLT has previous experience of working with MND. Following their assessment, therapy may help the person maintain speech for as long as possible, but they are likely to need further support at some point. The SLT can advise about the range of communication aids, depending on the person's needs and abilities.

See Section 2: What to expect and Section 5: What kind of support is available?

If you use a computer, internet facilities and social media, these can help bring the outside world into your home. This can help you locate information, advice, support from others affected by MND, entertainment and help you maintain contact with family and friends. You can also use social media and email to update those who support you, so they know what is happening and when they may be needed.

“I love the MND Association online forum. This is a great place to talk to other people about MND and take advice from others in similar situations.”

Our forum provides a safe place to share experiences and tips with other carers and people with MND. You can access the forum at: **<https://forum.mndassociation.org>**

No matter how difficult it may feel at times, try to get out and about with the person you support. As the disease progresses, this can take effort and energy, but can lift spirits.

See our booklet *Getting around on driving, transport and holidays*.

Where available, our branches, groups and Association visitors may provide opportunities for conversation, guidance and social contact.

See Section 11: How the MND Association can help you.

“I joined a local group so that I could get some support and guidance when the going gets tough.”

As part of a carer's assessment, ask about ways to maintain your own interests and hobbies. You may need time to do something away from the home, whether to take a break from caring, keep up with an educational course, maintain employment skills or just to feel like 'you'. Care support or respite care can enable you to take short regular breaks.

See Section 4: Carer's assessment and Section 5: What kind of support is available?

Sadness

You may feel intense sadness or grief from the point of diagnosis. Hearing that someone you love has a life-shortening illness is upsetting. This sadness is likely to continue due to:

- a general sense of loss as life changes
- the way your relationship begins to change with the person you support, as they become more dependent on you
- loss of intimacy, as the person becomes less able to touch and hold (especially if they are your partner)
- watching someone cope with increasing disability
- thinking about bereavement.

“We both spend a lot of time weeping.”

You may also feel sad about the how the situation will affect other members of the family. This can be particularly difficult if children are involved.

See Section 9: Support for children and young people for information about children and young people affected by MND in the family.

How do I manage this?

It can be tempting to hide your own feelings, to avoid upsetting the person with MND or those close to you.

“When things go wrong, I try to be happy and act exactly the same as before. I never let her see the pain it is causing me.”

Yet, these feelings may only get worse without release. If you cannot talk about this at home, try to find someone who will listen. If the feelings begin to affect daily life or you feel very low, you may need support. Ask your GP for advice. As with anxiety and fear, counselling may help.

See previous heading for Anxiety and fear.

“Some professionals seem oblivious to the emotional impact of change. I cried all the way through my ‘hoist training’ for example, but they just carried on to the end.”

If something catches you unawares and you get upset, people with you may not immediately understand, even professionals. Let them know why it’s affecting you, as you may just need a few moments to feel calmer, or ask for a different approach.

Helplessness

Feelings of helplessness are common when caring for someone with MND. Without a cure or a way to reverse the progress, it can feel relentless. Just as you find a routine of care that seems to work well, symptoms can appear unexpectedly and everything has to change again.

“I feel helpless, lost and terrified most of the time, regardless of the support I get. The outcome of this disease is inevitable.”

You may also have no previous experience as a carer. It can be difficult to adjust to the role and remain confident. This is not surprising when you consider:

- you have increasing levels of work to do
- being a carer is not necessarily something you would choose to do
- you need new skills, but have no idea where to get training or how to find time for this
- getting a break seems too difficult
- your standard of living may have dropped if your finances are affected
- you may not have enough support to help you as a carer.

How do I manage this?

This is a difficult role, and yet you do it. You are finding out, every day, that you can do more than you ever thought possible.

“I have always said I couldn’t look after anyone because of lack of patience. I didn’t want to and couldn’t face doing anything personal for anyone. Wow – did that have to change!”

Even if you have times of self-doubt, take pride in what you are achieving.

Keep these thoughts in mind:

- you are not superhuman or expected to be
- you may sometimes make a mistake, we all do (think of this as learning)
- there is no need to feel inadequate just because you are new at something
- asking for help is not failing, it shows initiative and organisation
- as an unpaid carer, you may put in more hours than a care worker.

The health and social care team supporting you both are a source of information and guidance. Contact a relevant professional if you need advice. They may not be able to respond immediately, so make contact as early as possible with any concerns you have.

“I take notice of what doctors, nurses and hospital staff are telling me.”

Where you have built a relationship with a professional, they will have a better understanding of your circumstances and those of the person with MND. This means they can advise in a way that suits your particular circumstances.

This is where regular contact with a hospice or specialist palliative care team can be valuable, as they will look at the needs of the person with MND, their carers and family too.

See Section 5: What kind of support is available?

Key points

- Emotions can be complicated and you may feel more than one at a time. Identifying what you feel is the first step towards managing these feelings if overwhelmed.
- Let those close to you know how you feel, including the person with MND where possible. You can all work better as a team if you know how and when to support each other.
- Tears and laughter are both allowed. They provide a good release and may give others permission to feel release too.
- Ask your GP or members of the health and social care team for help if you are troubled by difficult emotions on a constant basis. If you allow these feelings to continue unchecked, they may affect your health and wellbeing.
- Treat yourself with compassion and kindness when you can. Try and take some time each day, even just 20 minutes or so, to do something you enjoy. Read, go in the garden, feed the birds, enjoy a special coffee. Just a moment of being in the here and now can lift mood and help you find energy.

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:

3A: MND care centres and networks

6B: Complementary therapies

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.

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

Getting around: our booklet on driving, transport and holidays.

Making the most of life with MND: ways for someone with MND to maintain interests and hobbies for as long as possible.

Emotional and psychological support: our booklet about available therapies.

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8: Looking after yourself



This section suggests ways to think about your own wellbeing when supporting someone with MND.

Taking care of yourself can seem like an impossible task when facing the challenges of supporting someone with MND.

It is important to look after your own needs, yet you may:

- feel overwhelmed by demands
- have no time for yourself
- have other dependants or children who need you too
- try to always put the needs of the person with MND first
- have no energy left to care about your own needs and wants.

“Advice about looking after yourself, taking breaks and so on, is the most difficult to follow. It’s perfectly sound – we understand the good sense employed – just impossible to accomplish.”

Physical and psychological health can be affected by taking on a caring role. This may result in you being unable to provide support, even if this is still your wish.

As difficult as it may be, there may come a time when you need to ask for and accept support. You may need assistance with care tasks or personal support to manage the emotional demands.

Practical chores, exhaustion and the unpredictable nature of MND may make it hard for you to take time out.

Providing care may be more difficult and intense than you ever imagined. MND is not just about the person diagnosed, it affects you too and you deserve support.

“In effect, you are living two people’s lives.”

You may also feel as if you are losing control of the situation. MND is complex and ever changing. This can be stressful, but taking a practical approach can help you feel calmer and more able to cope.

Think about each difficulty that arises and what could help. Where appropriate, seek advice from the most appropriate member of the health and social care team who support the person with MND. There may be more than one solution, but try the simplest first, if it feels safe to do so. It may do the job and making life as easy as possible is important when you have so much to do. By letting professionals know how you feel, they can understand and offer help for you too.

“When you become a carer, you stop thinking about yourself and your own wellbeing completely. Looking back, I can see how I let myself lose my identity, because I refused to accept or research the help that was available until it was too late.”

Working as part of a team

With the person you support

If you can work as a team with the person you support and be flexible with routines, life with MND may be a little easier to manage.

This is not always possible to achieve. Sometimes, relationships are difficult and MND tends to make this harder. Even where the relationship is close, the person with MND may have problems with speech and communication. This makes it more tiring to remain aware of each other's needs. Discussion takes longer and can be frustrating for you both, but assessment by a speech and language therapist can help. There are therapies to help maintain speech for as long as possible and communication aids to assist when further support is needed.

See Section 2: *What to expect* and Section 5: *What kind of support is available?*

Communication barriers can also happen if you feel tempted to lighten the burden for the person you support. For example, you may keep your own feelings and needs hidden, as a natural protective response. Yet, this is unlikely to help either of you in the long term.

“Understandably, as a carer, you want to praise the person’s bravery and initiative, you don’t want to say ‘help’”

Open communication helps you both to face the challenges ahead as a team and support each other. If the person with MND finds it hard to discuss their condition, a member of the health and social care team may be able to facilitate a difficult conversation.

This can be important if someone has a determined approach to the disease and resists external help. In an effort to make life as normal as possible and keep everything around them the same, the person with MND may:

- be reluctant to use equipment and aids that support disabilities
- unwilling to accept help from visiting care workers
- refuse any form of respite care.

“My wife will not go into respite care...I have guilt thrown at me if the idea is even suggested.”

They may not realise the impact of this on you. As they become more dependent, the more you have to do. There is a limit to anyone's capacity – especially if night care is also needed and sleep is disturbed.

A needs assessment for the person with MND and a carer's assessment for yourself can be useful. Carried out by adult social care services, these assessments work out what your current and future needs are likely to be. You will also receive advice on services in your area. This may also help the person with MND to recognise the value of available support, including help from care workers.

See Section 4: *Carer's assessment.*

You and the person you support can have an assessment of your needs together if you wish. This may be helpful in encouraging discussion to gain appropriate support for you both. However, you may find it difficult to be open about the challenges you face as a carer in front of the person with MND. In this case, you can ask to be assessed separately. Either way, try to be honest about your needs.

If you do have a joint assessment, telling the professional how you feel in the caring role can also help explain this to the person you support. The assessment process can help the person with MND understand why additional support and equipment may become necessary. Other members of the health and social care team may need to repeat these messages over time.

If the person with MND shows changes to their thinking and behaviour, they may become set on one viewpoint and show a lack of empathy. You are likely to need additional support. Seek advice from their neurologist or specialist MND nurse, as screening tests can help work out what is happening.

See our booklet, *Changes to thinking and behaviour with MND*.

With family and friends

Care workers often share responsibilities with other staff and, even on long shifts, they go home and rest. The pressure on you as an unpaid carer can be greater, especially if you live with the person you support, so don't feel afraid or ashamed to ask for help. You may not be able to shoulder everything alone.

“Accept help when it is offered. I am getting better at this. I want to be able to do it all by myself, but I just can't. I won't be able to survive if I do.”

Friends and family may be more willing to help than you think, but unaware of how they can make a difference. Let them know and keep a list of chores to offer if they volunteer help. They may welcome this, as it means they can do something positive in a situation that challenges them too.

Some tasks are easy to give to others, such as:

- washing clothes
- ironing
- preparing a meal
- shopping
- internet shopping
- vacuuming
- gardening chores.

“Don't be afraid to ask for help. It's surprising what people are ready to do, but won't in case they are intruding.”

Some may be able to provide care cover or just keep the person company if you need to go out. This can help you take a break or get tasks done outside of the home.

If you do not have a network of family and friends for support, assessment and review by the health and social care team may help answer a variety of needs. This may result in assistance from care workers, who can help around the home or with personal care for the person you support.

With health and social care professionals

It is important that all professionals involved in support of the person with MND respect you as a member of the care team. Speak up if something worries you. You know more about daily care and the way the disease is progressing than they do.

You may choose to act as an advocate for the person with MND. This means you help to raise awareness of their needs and act as their 'voice' in certain situations. This may include representing their best interests if they become unable to make decisions or communicate for any reason. However, you need consent from the person with MND before professionals can provide you with any of the person's medical information. If you do not wish to act as an advocate, health and social care professionals can assist.

Encourage the person you support to give consent to their GP and health and social care team to share medical information with you. It can help to have a signed letter of consent in case the person with MND becomes unable to communicate for any reason. If you need to seek guidance on how to manage symptoms, this can make these conversations easier. Anything you can do to reduce stress for yourself is important.

When ready, you may want to think about other ways to advocate for the person you support. See information sheet 14A - *Advance decisions to refuse treatment (ADRT) and advance care planning, which includes guidance on power of attorney.*

Use the health and social care team for your own support too. If you feel there is guidance they can offer, do ask.

See later heading *Health and wellbeing.*

“There were weeks when we were going to hospital three separate days to see three different people.”

There are many ways the health and social care team can assist if you are under pressure.

A good example is asking them to group appointments – if they are working in a co-ordinated way, as part of a multidisciplinary team, this should be possible. This happens at MND care centres and networks, and many neurological clinics. Seeing several professionals in one day will still be tiring for both of you, but avoids multiple journeys and gives time to rest before the next appointment day.

Carers have rights, so feel confident about asserting these if you need help. Following a needs assessment for the person with MND and a carer’s assessment for yourself, you should be linked to wider support and possibly help with care.

See Section 3: *Your rights as a carer* and Section 4: *Carer’s assessment.*

How do I get everything done?

The simple answer is: *don’t even try.* Taking on a caring role inevitably means taking on more work than you did before. This is likely to increase with MND as symptoms progress and the person you support becomes more dependent.

Instead of trying to accomplish it all, consider whether each task is:

- essential
- important
- needs doing, but not immediately
- would be nice, but not needed.

Be honest with yourself, as there will almost certainly be jobs that are not vital, or that can wait.

“I felt that by doing everything myself, in relative secrecy, I could somehow pretend to the outside world that things weren’t so bad.”

Even if you take pride in doing tasks a certain way, it helps to think about how you work. Being flexible about chores and routines can release time for you and the person with MND to do the things you really want to do.

This is important, as the person you support may have problems with fatigue. There may be better times of day, when their energy is higher – save these times for preferred activities where possible. These might be good times to do things together or for family and friends to visit.

Health and wellbeing

What to look out for

As a carer, your health may be affected. Signs of stress may include:

- extreme tiredness
- irritability
- difficulty sleeping
- headaches
- muscle tension
- unexplained aches and pains
- uncontrolled or repeated bouts of crying.

You may also receive injuries from moving and handling, as the person you support may have mobility problems or experience falls.

How do I manage this?

Let your GP and GP surgery staff know that you are a carer. Most surgeries will then place a marker on your medical record, which helps them monitor and respond to your needs. This may result in:

- more suitable appointment times
- home visits if appropriate
- health check-ups to monitor your wellbeing
- advice on treatment or care for the person you support
- information about support, such as respite care to give you a break
- you being recognised as an expert partner in the care of the person with MND.

Your GP may see signs of stress that could lead to ill-health. Try to take the advice given, even if you feel under pressure.

“I needed someone in authority to tell me that after seven and a half years of caring and not sleeping properly, it was okay to take a break.”

It can help to arrange care cover so you can attend regular GP appointments on your own. This way, you can talk openly about how you feel with the focus on you. Try to prepare for these appointments. You may find the following questions useful:

- Is your health worrying you?
- Are you getting enough sleep?
- Do you have any aches or pains that need to be explored, such as back ache?
- Are you feeling continually stressed or anxious?
- Are your moods consistently low?

- Do you feel isolated or lonely?
- Are you worried about money?
- Is your sex life affected?
- Do you need help with care tasks?
- Do you know how to access emergency services if needed?
- Can the GP help with plans for emergency care cover if you fall ill or have an accident?
- Can the GP advise about local support groups and carer centres?

All of these questions help your GP to build a picture of your needs and advise in an appropriate way.

How can I help myself?

“As a person forever on the go, I have learned to stop. I love to lie on our old tatty green sofa in the kitchen, facing the open doorway, where I can see and smell our lovely garden, now badly in need of cutting back (see, there I go, to-do list starting already). I give myself twenty minutes there sometimes – occasionally I doze, which is not a bad thing. Often the cat joins me and I find his presence oddly comforting. I am learning to take ease when I can. I have to. This is hard for me.”

If you are the main carer, the burden of full-time care should not be underestimated. No-one can be on the go 24 hours a day, seven days a week. Don't feel guilty about looking after your own wellbeing.

It can help to discuss your needs with the person you support, so they understand how MND affects you too.

The following suggestions may help you achieve a better quality of life while caring. Not all of these suggestions will be right for you and there will always be the issue of finding time to look after your own needs. However, if you become exhausted, you may be unable to support the person with MND, even if this is your wish.

Ways to achieve 'me time'	How?
<p>Carer's assessment</p> <p><i>"At the time of the assessment my needs were not as great as now, but extra help has come as needs arise."</i></p>	<ul style="list-style-type: none"> • Ask for a carer's assessment through your local authority, or in Northern Ireland through your local health and social care trust. Assessment enables you to find out about social care services, including respite care and care worker support. <p><i>See Section 4: Carer's assessment.</i></p> <ul style="list-style-type: none"> • Before the assessment, keep a record of what you do, even if you can only find time to do this for a short period. It can help the assessor see the level of support you give. <p><i>See our Care summary in the write-on pages at the back of this guide to help you track care tasks.</i></p> <ul style="list-style-type: none"> • At the assessment give a detailed picture of your needs and how a 'bad day' feels. This may help to achieve the best possible support.
<p>Rest and relaxation</p> <p><i>"Our local hospice can offer massages."</i></p>	<ul style="list-style-type: none"> • Rest when you can and let non-essential tasks wait. • Accept help when offered and use the time for you. • Pace yourself where possible and be flexible with routines. • Try not to set goals or standards that are difficult to achieve. • Is there a day centre or local hospice where the person with MND can have a regular session, such as complementary therapy? You may be able to enjoy a session with them or use this time for yourself.
<p>Breaks and holidays</p> <p><i>"I may need a break in the future and will accept help if offered then."</i></p> <p><i>"He attends a hospice once a week and transport is provided to bring him back."</i></p>	<ul style="list-style-type: none"> • At your carer's assessment, find out about respite care, care worker support and any carer break schemes that may be available at your carer assessment. • If you have support from family and friends, can they cover care for you to have a weekend or week away? • If you don't want to go away alone, think about a holiday with the person you support in accessible accommodation. A change of surroundings can be valuable.

Ways to achieve 'me time'

How?

Hobbies and interests

"I joined a creative writing class and try to cycle there once a week...for those two hours I really don't think about anything else."

- Can family, friends or care workers provide regular cover at a set time for you to attend a social club, course or other activity?
- Can you follow an interest or course of study at home, so you can dip in and out as time allows?
- If the person you support has a nap, is distracted by a film or seems settled, can you occasionally take an hour to do something you enjoy and leave the chores?

Eating well

"I care for my wife 24 hrs a day, but get help three times a day for meals."

- Cook in batches and freeze meals to save on preparation time, or use foods that are quick to prepare.
- If the person with MND has an appointment with a dietitian, ask for advice about your own needs and energy levels too.
- If the person with MND uses tube feeding, there may be a temptation to eat separately if you feel guilty they can't eat by mouth. Discuss this with them, as they may not wish for either of you to feel isolated.

See [Eating and drinking with motor neurone disease \(MND\) for ideas on easy to swallow meals for the person with MND, as used by other carers.](#)

Staying fit

"I've never been very good at exercise, but if I'm going to get through this I've got to make some attempt to keep fit."

- Caring can be physical, but it's not the same as focused exercise to meet your personal needs. Always ask your GP for advice before beginning a new exercise routine.
- Exercise may feel tiring at first, but improving your fitness can help to improve energy levels and stamina.
- You may be able to access help towards gym membership through your carer's assessment (depending on your financial assessment).
- If you find it difficult to leave the person with MND, there are lots of exercise routines available on DVD or through the internet. If you are not used to exercise, always select a beginner course.
- Getting fresh air can be important if you spend a lot of time inside with the caring role. Simply going for a walk can help fitness and provide a short break. If the person with MND has a scooter or wheelchair, you may be able to go out and enjoy time together.

Ways to achieve 'me time'	How?
<p>Training and learning</p> <p>"It's not something you choose to do: it's thrust upon you."</p>	<p>Ask the health and social care team for specific training in care tasks if you feel unsure. Working as safely and efficiently as possible can reduce risks and the stress you may feel.</p>
<p>Keeping in touch</p> <p>"As a carer you can feel quite lonely. Making time to be with other carers on a regular basis can help."</p> <p>"I love the MND Association forum. This is a great place to talk to other people about MND and take advice from other carers."</p>	<ul style="list-style-type: none"> • Our branches and groups offer a warm welcome and opportunities to share experiences and tips with other carers and people with MND. • Contact our helpline, MND Connect, to find out your nearest branch or group or look online at: www.mndassociation.org/branchesandgroups • You can visit our online forum at: https://forum.mndassociation.org to view posts or join an online conversation. If you find it difficult to leave the person you support, the forum may be a good way to stay in touch with other carers.
<p>Using technology</p> <p>"I like things that are really easy to access and read online. One click and you know what to do – don't make me keep searching!"</p> <p>Use our <i>Care information finder</i> to search quickly for our online resources at: www.mndassociation.org/careinfofinder</p>	<ul style="list-style-type: none"> • Mobile technology, such as smart phones and tablets, can help you access a wide variety of applications, known as apps. These include apps for carers to share information with other carers, track tasks or schedule appointments. <p>See www.mndassociation.org/apps for links to suggested apps.</p> <ul style="list-style-type: none"> • Apps can also provide a range of facilities for the person with MND, including text-to-speech programmes for communication. • Internet shopping can reduce the need for shopping trips and bring groceries and supplies to your door. • Social media can help you maintain contact with the wider world, friends, family and interests. • If you have internet access, you have instant access to information, including our own about MND. <p>See www.mndassociation.org/publications for downloads of our guides and information sheets.</p> <ul style="list-style-type: none"> • Our online forum provides a safe place to view or share experiences and guidance with other carers and people living with MND. <p>See https://forum.mndassociation.org</p>

Ways to achieve 'me time'	How?
<p>Telecare and environmental controls</p> <p><i>“He would communicate by using his chin to nudge a switch.”</i></p> <p><i>“He had a special TV and computer so he could control things more easily.”</i></p>	<ul style="list-style-type: none"> • When the person with MND is being assessed for their care needs, ask about equipment to send messages to a health monitoring service. If you cannot be with the person at all times, this can ensure assistance in case of a fall or other urgent situations. There may be a charge for this. • Adapted switches and controls can help the person with MND remain independent for as long as possible. Environmental controls can help the person with MND control devices around them, such as the television, telephone, computer and lights.
<p>Giving yourself permission</p> <p><i>“I have had to learn to give myself permission to be good to myself.”</i></p>	<p>It is easy to place your own needs second when caring, but you have the right to look after your own wellbeing too. Not just food, drink, rest and hygiene, but general health, sense of purpose and emotional needs. Try not to feel guilty when you manage to find a little time for yourself. When giving so much, it is okay to claim space for you.</p>
<p>Helping the person with MND to feel secure</p> <p><i>“We didn’t know what MND was, so to have an Association visitor with knowledge about it, to sit and talk with us was so important.”</i></p>	<p>If the person with MND resists external help of any kind, including equipment, assistance from care workers or respite care, you may need professional support to help open discussion. The health and social care team may be able to help the person feel more secure about future care decisions. A joint needs assessment for the person with MND and carer’s assessment for yourself can also be helpful.</p> <p><i>See Section 4: Carer’s assessment and Section 5: What kind of support is available?</i></p> <p>Where available, our Association visitors can also facilitate discussion about needs for both of you and how to access support. Or you can contact our MND Connect helpline for guidance.</p> <p><i>See Section 11: How the MND Association can help you.</i></p>

Key points

- Asking for help, with care tasks or emotional support, does not mean defeat. You are simply acknowledging the breadth of the caring role and that support may be necessary.
 - Accept that your needs matter too.
 - Find out where to go for the most appropriate type of help.
- See Section 5: What kind of support is available?*

- Let family and friends know how to help, as they may feel uncomfortable asking what they can do.
- Pace yourself – not all tasks are essential.
- Register as a carer at your GP surgery, so they can better support you.
- Ask adult social care services for a carer's assessment for yourself and a needs assessment for the person with MND (if they agree) to work out how support can be arranged.
- Always keep in mind how you have adapted to huge changes already. We are often capable of more than we realise.

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9: Support for children and young people



This section provides guidance to help you support children or young people who are close to the person with MND or become involved in care tasks.

How do I explain MND to children and young people?

When someone is told they have MND, it can be confusing and shocking for the whole family. If children and young people are involved, it can feel particularly difficult.

“We’re trying to hide it from the kids, as we’re unsure what to say or do.”

Our natural instinct is to protect younger members of the family from distress or worry, but MND is not something that can be hidden or disguised. Children and young people will see the disease progress and symptoms will get worse.

“I can’t remember being told that mum had MND, just feeling confused and that everything was changing.”

They may try to find out information on their own, often through the internet, which can be unreliable or cause alarm.

If children and young people are left to their own imaginations, they may blame themselves or feel isolated.

“I blamed myself for dad dying for a very long time. I saw it as my fault he’d got ill.”

How you explain MND to a young person will depend on their age and ability to take in new information. Try to use words that will be clear to them. It can help to talk about the physical effects of the disease so they know what to expect.

For example, if the person with MND has problems with facial expressions, this may not be obvious to the young person. They may even think they have done something wrong. To help them, you could say, ‘The muscles in Grandad’s face aren’t working properly. He’s not cross with anyone – he just finds it difficult to smile.’

Key facts to help a young person are:

- it’s no-one’s fault if someone gets MND – nobody is to blame
- it’s not caused by something that someone does
- you cannot ‘catch’ MND by touching someone who has the disease

- young children do not get MND and although younger adults have been diagnosed, most are 50 years or more when this happens
- there is a type of MND where more than one person in a family has had it, but this is extremely rare.

As the disease progresses, keep communication open with children and young people. If they know what is likely to happen next, they will be more prepared and less likely to feel shock as a symptom gets worse.

Is there anything that can help me with this?

The following table explains how we provide information and support to help children and young people.

See *Further information at the end of this section for details about how to access our publications and services.*

What we provide:	What this can do:
Telling people about MND	A booklet to help people with and affected by MND explain the diagnosis to family, children, friends and professionals.
Why is everything changing?	Our storybook for young children, with three gentle family stories about MND. These can help begin conversations about a diagnosis. You can also listen to them read aloud on our MND Buddies hub (see next row).
MND Buddies activity hub:	Animal characters in this online hub act as guides, taking children through facts, games, stories and other activities about MND in a kind and interactive way. See www.mndbuddies.org
When someone close has MND	An activity workbook for children aged 4 to 10. The content can be introduced gradually, to help a trusted adult communicate with the child. The activities help the child develop ways to cope with the changes that MND brings.
So what is MND anyway?	A guide to help young people up to 18 understand what a diagnosis of MND means and what to expect if a member of their family has been diagnosed. The aim is to help them feel more prepared and aware of available support.

What we provide:	What this can do:
<p>Web pages for children, young people, parents and guardians</p>	<p>Find family resources at: www.mndassociation.org/cyp</p>
<p>Young Connect</p>	<p>Young people can contact our helpline for support and information:</p> <p>Telephone: 0808 802 6262 Email: youngconnect@mndassociation.org</p> <p>Or email our contact for children and young people's services: cyp@mndassociation.org</p>
<p>Link with ChildLine</p>	<p>If a child or young person affected by MND contacts ChildLine for information about the disease, they will be referred to our Young Connect helpline.</p> <p>If a child or young person contacts our helpline because they need counselling or emotional support, we refer them to Childline.</p> <p>ChildLine telephone: 0800 1111</p>
<p>Young Person's Grant</p>	<p>We offer grants to young people aged 18 or under, and to young carers aged 16 or over. A family member, health and social care professional or the young person can submit the application. These one-off grants can be used for a range of support, such as:</p> <ul style="list-style-type: none"> • days out • additional tutoring • out of school activities • driving lessons • a laptop • decorating their room at home. <p>For details, contact our MND Connect helpline: Telephone: 0808 802 6262 Email: mndconnect@mndassociation.org</p>
<p>Useful organisations for children and young people</p>	<p>See Section 12: Useful organisations, which includes a separate list of providers for children and young people.</p>

Who are young carers?

A young carer may be the child, grandchild, brother, sister, other relative or friend of the person with MND.

They may live with the person who has MND or live nearby and visit. Finding a balance between life and care can be difficult when young people are involved.

“It’s hard to know when to ask the girls for help and when not. They have seen things they shouldn’t at their age, but what is the alternative? I think the strain on them is the greatest, but they are a credit to themselves. I wish I had more time for them.”

Once children and young people know what is happening, they often get involved in care tasks in some way. This can happen because:

- they want to feel involved and offer their help
- they want to spend time with the person who needs care and begin to do things for them
- there are helpful things they can do around the house while you are caring for the person with MND
- you need help as the main carer
- they live with the person who has MND (and you may not)
- the person’s care needs become complex and need additional support
- they live with a single parent who has MND and they become the main carer.

“I didn’t think of myself as a young carer – I just did what had to be done. I didn’t really have a choice.”

What do young carers do?

Young carers may do all of the tasks that an adult carer would do, but this is not always appropriate. This is where assessment of their needs becomes very important to ensure the right support is in place.

Depending on the type of care needed, young carers may get involved in:

- helping younger brothers and sisters
- housework or laundry
- shopping for food and supplies
- making meals
- helping the person with MND to eat and drink
- giving medication
- helping the person with MND to get washed and dressed
- providing emotional support and company.

“At first nothing much changed, but gradually I had to help out more and more.”

A young person’s needs assessment is usually arranged through your local authority in England or Wales, or your local health and social care trust in Northern Ireland. Contact them to find out what you need to do and book an appointment.

The assessment will consider the impact on their wellbeing, school work or employment, social life and interests. A care support plan will be developed in agreement with the young person and their parents or guardian.

See later heading, *Rights for young carers* for more information about assessing the needs of children or young people who get involved in caring.

How will being a young carer affect their life?

Young carers can be affected in some or all of the following ways:

- the feeling that caring has taken over their life
- that the expectation on them is overwhelming
- attending school or work feels difficult
- friendships may be tricky to manage if there is less time to socialise
- they may feel embarrassed to bring friends home if they worry about equipment installations, changes to their environment or the person's disabilities
- they may feel jealous of friends whose lives seem 'normal'
- family relationships are often challenged by the effects and demands of the disease
- they become very tired and irritable (especially if dealing with puberty at the same time)
- they feel their needs always come second
- they may worry about money if the family are under financial pressure – particularly if one or both parents have to leave work because of MND.

“It’s very difficult trying to study for A-levels, keep up with friends, look after my dad and help mum look after him too. I feel a lot of responsibility and think about things that wouldn’t even cross my friends’ minds.”

As with adult carers, young carers can feel many different emotions, and their emotions can change rapidly. They may feel down one minute and up the next.

When ‘up’, they may feel:

- happy they can help make a difference
- proud of an achievement
- a sense of control through being involved
- positive about themselves and what they can do
- closer to the person with MND
- that today is a good day or even just a ‘normal’ day
- a growing sense of independence
- they are building memories with the person who has MND.

When ‘down’, young carers may experience feelings of:

- sadness
- anger
- worry
- fear
- stress
- guilt
- embarrassment
- neglect
- indifference or apathy.

Your own emotions are also likely to be affected by trying to support more than one person at a time, while dealing with the demands of MND.

“As a parent, I worry all the time that if anything happens to me, she’ll have no-one. I feel anxious, inadequate and constantly torn between our daughter and caring for my husband. Her life is a reduced version of what it could have been.”

Children and young people can be resilient and discover their own strengths when someone close is diagnosed with MND. If they find it particularly difficult, these feelings may become intense or overwhelming. In some cases, this can lead to extreme reactions, which may include:

- becoming withdrawn or depressed
- poor attendance or falling grades at school
- eating disorders
- self-harming
- drug or alcohol abuse
- being bullied or bullying
- disruptive or aggressive behaviour
- running away.

If you need advice about support for children or young people in your family, talk to someone as soon as you can. You may wish to contact our MND Connect helpline who can direct you to our own and external services:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

There are many other organisations that can also help, that offer services designed for children and young people. They can also advise you on how to find support for younger members of the family if you have concerns.

See the end of this section for organisations that support children and young people.

There may be waiting lists, even with services for children and young people. If a service is stretched, you may have to wait for support, which can be difficult if you are worried.

“What’s happening at home is having a very bad effect on my daughter’s exams. I feel so guilty.”

If the child or young person needs immediate support, they may find it helpful to contact:

- ChildLine: **0800 1111**
- Samaritans: **116 123**
- Our contact for children’s services at the MND Association, **cyp@mndassociation.org** which includes a way of gaining fast referral to counselling through Barnardo’s
- Our YoungConnect helpline, part of our main MND Connect helpline service. They can offer support and information:
Telephone: **0808 802 6262**
Email: **youngconnect@mndassociation.org**
- Their teacher or head teacher, who may be able to arrange support services through the school.

See later heading in the section, *School, study and work.*

Rights for young carers

The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty that grants all children and young people (aged 17 and under) a comprehensive set of rights. All UK government policies and practices must comply with these rights.

The rights included in the UNCRC are wide ranging, but some are important in terms of UK laws that support young carers. Children have the right to:

- a childhood
- an education
- health and health services
- be heard, listened to and believed
- be protected from physical and psychological harm
- privacy and respect
- have their views taken into account when decisions are made that affect their lives.

Further detail can be found at: **www.unicef.org.uk/UNICEFs-Work/UN-Convention**

This means young carers have the right to information, choice and wellbeing. In order to protect these rights in the UK, young carers can have their needs assessed, similar to your own carer's assessment.

Assessment of a young person's needs leads to a care and support plan, which may include a range of support.

For example:

- practical assistance in the home
- support to enable recreational activities for the young person
- support to enable holidays
- equipment to help communication and contact, such as a mobile telephone.

Some services and assistance may be free of charge for children and young people. Where service or equipment charges do apply, the parents or guardians are financially assessed to see how much they may need to pay. However, this may depend on the age of the young person (under 16), whether they are employed and how they have been assessed.

The following information looks at rights to assessment for young carers in England, Wales and Northern Ireland.

Young carers' rights in England

Under the new Care Act 2014, all young carers under the age of 18 have a right to assessment regardless of who they care for, what type of care they provide or how often they provide it. You can find the full Act online. Search for *Care Act 2014* at:

www.legislation.gov.uk

An assessment can be requested through your local authority, but should be offered if there is an 'appearance of need'. This appearance of need may be identified as a result of a care assessment for the person with MND or a carer's assessment for yourself.

The assessment looks at why the child or young person is involved in care tasks, what may need to change and ways to help the family prevent the need for the child to take on inappropriate responsibility.

Young carers' rights in Wales

In Wales, local authorities have a duty to assess any 'child in need' under the age of 18, for any services they or their family may need. A young carer with significant caring responsibilities would be recognised as a child in need.

This would be done through a Children Act Assessment, but young carers who are 16 or older can request a full carer's assessment if they wish. The aim of any service provision to young carers is to ensure they can achieve or maintain a reasonable standard of health and development.

See Section 4: Carer's assessment and Section 3: Your rights as a carer for more on carer rights in Wales.

Young carers' rights in Northern Ireland

In Northern Ireland, young carers up to 18 are assessed under the Children (NI) Order 1995, using a process called *Understanding the Needs of Children in NI* (sometimes known as UNOCINI).

If aged 16 to 18, a young carer can ask for a full carer's assessment under the Carer and Direct Payments Act 2002, but it may be in their best interests to use the process mentioned above.

You can request an assessment for a young carer through your local health and social care trust. When assessing a young carer's needs in Northern Ireland, the aim is to help them avoid levels of responsibility for caring that could impact on their health and wellbeing.

For more information about the laws governing assessment in Northern Ireland, see: **www.nidirect.gov.uk/an-overview-of-carers-rights**

School, study and work

Some young people prefer to keep their home life private, but it can help to let their school or employer know what is happening.

What can their school do?

If a young carer is struggling to keep up with schoolwork or has missed any school as a result of caring, it is best to keep the school informed.

“Watching her granddad get worse week by week really affected her, but her school has been arranging counselling.”

Pastoral services in schools provide support for a range of practical, emotional and behavioural needs. This type of support is often provided by teachers, a school nurse or even other pupils who act as mentors.

Ask the school what they offer and how this might help. Once aware of challenges the young person may face, they may provide a pastoral care plan (following discussion with the young person’s parents or guardian - which may include you). This can help the young person feel more secure at school and gives them a point of contact if they feel worried or upset about anything.

The school nurse is a useful contact, who can:

- support and provide advocacy for the young person
- look at what support can be given if there is an emergency at home
- refer the young person to wider support services if needed.

Supported by the Department of Health, the Carers Trust and other partners, a programme has been established to train school nurses to become ‘Young Carer Champions’. This aims to improve support for young carers in schools and ensure they and their families are linked into and receive support from services they may need.

There is usually a lead teacher at each school who is nominated as main contact for students who are young carers. It is worth finding out who this is.

Teachers can help by:

- allowing extra time for homework
- arranging support services through the school, such as counselling sessions
- providing information about external support services in the local area
- introducing a young carer to other young carers in the school for peer support
- advising about school commitments and homework, especially if an emergency happens at home.

Young Carers in Schools programme

This is an initiative across England to make it easier for schools to support young carers. Run jointly by Carers Trust and The Children’s Society ‘Young Carers in Focus’ partners, it provides:

- guidance for school staff and teachers to help them identify and support young carers
- opportunities for teachers, young carer services and health and social care professionals to share knowledge
- the Young Carers in Schools Award, enabling schools to gain recognition for good practice.

Ask the relevant school to find out if they are involved or search for young carers in schools at: <https://carers.org>

What can employers do?

If a young carer is employed, in either part-time or full-time work, they may worry about their job being affected by the demands of caring. In most cases, employers are willing and able to help. They may be able to:

- adjust working hours to suit the caring role
- allow flexible working, so hours can change when appropriate
- provide some form of carer’s leave (this may be unpaid, but could be useful in urgent situations).

Which professionals support young carers?

Young carers are likely to meet a wide range of professional people or groups during their caring role, in a variety of locations. This may include home visits where appropriate and with your permission.

These professionals can be involved with:

- the direct health or social care of the person with MND
- support for young carers
- school or college life, if the young person is still a student.

The following list provides a brief explanation for each of these contacts:

Person or group:	What they do:
Lead teacher	These teachers are appointed by a school to lead in a particular area. Often, a lead teacher becomes the main contact for students who are young carers.
School nurse	Often involved in pastoral care within a school, the school nurse can provide support or refer children and young people to wider health and social care assistance where appropriate.
Education Welfare Officer (EWO)	An EWO identifies problems with school attendance, but also looks at possible solutions. They can help families get benefits for school meals, transport or clothing. They also have knowledge of other local services and professionals.
Social worker	A member of staff from adult social care services, who helps people with their social care needs. They can assess the needs of young carers, offer support and help arrange services, as appropriate.
Children and Adolescent Mental Health Services (CAMHS)	<p>Children and young people and their families can be referred to CAMHS if children need professional help to cope emotionally with daily life. CAMHS can help with the effects of traumatic events or diagnose and treat serious mental health problems.</p> <p>To find your local CAMHS service:</p> <ul style="list-style-type: none"> • speak to your GP who can refer you (there may be a waiting list if the service is stretched) • search online for <i>Child and Adolescent Mental Health Services</i> in your area.

Person or group:	What they do:
Carer's centre	<p>A local carer's centre can provide information about services for carers and young carers, in your area. Contact your local authority or in Northern Ireland, your local health and social care trust, to find your nearest centre.</p>
Health and social care professionals	<p>Many health and social care professionals will be involved in the care and treatment of someone with MND and young carers may meet a wide range, especially if care becomes complex and professionals make home visits.</p> <p>See Section 5: What kind of support is available? for a list of these professionals with an explanation of each role.</p>
Multidisciplinary team (MDT)	<p>An MDT is a team of health and social care professionals from different disciplines, who work together in a co-ordinated way to provide care and treatment.</p>
MND care centre or network	<p>The MND Association has established and part-funds MND care centres and networks across the UK. The centres are usually based in hospitals and the networks operate as outreach teams. They provide co-ordinated care through a team of health and social care professionals (see multidisciplinary team below).</p> <p>See Section 5: What kind of support is available?</p>
Hospice staff	<p>Hospices are not just about end of life care in the final stages. With a life-shortening illness like MND, hospice and specialist palliative care teams provide a wide range of services to maintain quality of life, from the point of diagnosis onwards. This type of care includes support for families and young carers. This can help young people cope with difficult situations and learn how to deal with grief in the future.</p>
Youth workers and youth advice services	<p>These provide advice and support on a wide range of issues for young people. Contact your local authority or in Northern Ireland, your local health and social care trust, to find out contacts in your area.</p>

Person or group:	What they do:
Young carer projects	A huge number of special projects exist for young carers across the UK. These may provide activities, support or information. Contact your local authority or in Northern Ireland, your local health and social care trust, to find out what may be happening in your area.
Young carer festival	This is an annual weekend festival held in Hampshire and attended by young carers from all over the UK. It provides an opportunity for young carers to have fun and take a break, in the company of others who have a similar experience of life. Find out more through the Children’s Society at: www.youngcarer.com

Support for you

Supporting someone with MND is challenging, but adding dependent children into the mix can stretch the caring role to its limits.



“MND has come as a massive shock and taken over my life. I had to leave my job as coping with four children and the progression of dad’s MND was just too hard.”

If you feel you need help to manage all the demands, ask for a carer’s assessment from your local authority or in Northern Ireland from your local health and social care trust.

See Section 4: Carer’s assessment and Section 8: Looking after yourself.

Key points

- Discussing MND with children and young people may feel difficult, but there is less chance they will feel isolated or blame themselves if they are kept informed.
- Try to ensure children and young people accept that no-one is to blame for MND.
- If an assessment of need has not been offered to the young carer, you can request one from your local authority or, in Northern Ireland, your local health and social care trust.
- Children and young people can learn life skills from care tasks and may find it positive to be involved.
- A lead teacher who supports young carers, or a teacher that the child trusts, can offer practical and emotional support at school.
- If a young person is employed, they may find it useful to let their employer know what is happening and find out about flexible working.
- If you are worried about how a child or young person is coping, ask your GP for advice. There may be a specialist organisation that can provide appropriate support. You can also contact our MND Connect helpline for guidance towards relevant help.

Further information

We produce a wide range of publications about MND and the support that may be needed. This includes resources for children, young people, parents and guardians. See **page 87** for details about these resources.

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.*

Young Connect

Young people can also contact our helpline for support and information:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

Or our services for children at the MND Association at: **cyp@mndassociation.org** which includes fast referral to counselling through a collaboration with Barnardos, where this would be appropriate.

MND Association - Young Person's Grant

We offer grants to help young people and young carers affected by MND. Contact our MND Connect helpline as listed on this page.

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>

Please note, this forum is designed for adults to share information and you need to be 18 years or older to register.

Information for professionals

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

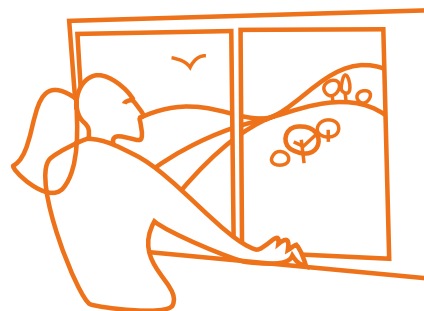
www.mndassociation.org/professionals

Useful organisations for children and young people

We provide a list of suggested organisations who offer services for children and young people in this guide.

See Section 12: *Useful organisations, which includes a separate list of providers for children and young people.*

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. 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.

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

“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.

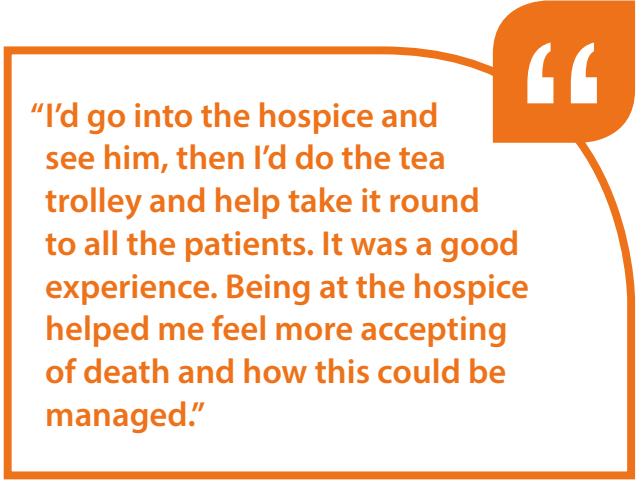
Assisting with care tasks may need to be discussed with the health and social care professionals involved. Find out what you can and cannot do in the circumstances, as health and safety may need to be considered. However, in most cases your help will be welcomed.

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 our booklet *Finding your way with bereavement for 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

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.

Emotional and psychological support: our booklet about available therapies.

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.

Finding your way with bereavement: Our booklet to support during grief.

Bereavement support online: see our page about seeking support during bereavement at: www.mndassociation.org/bereavement

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:

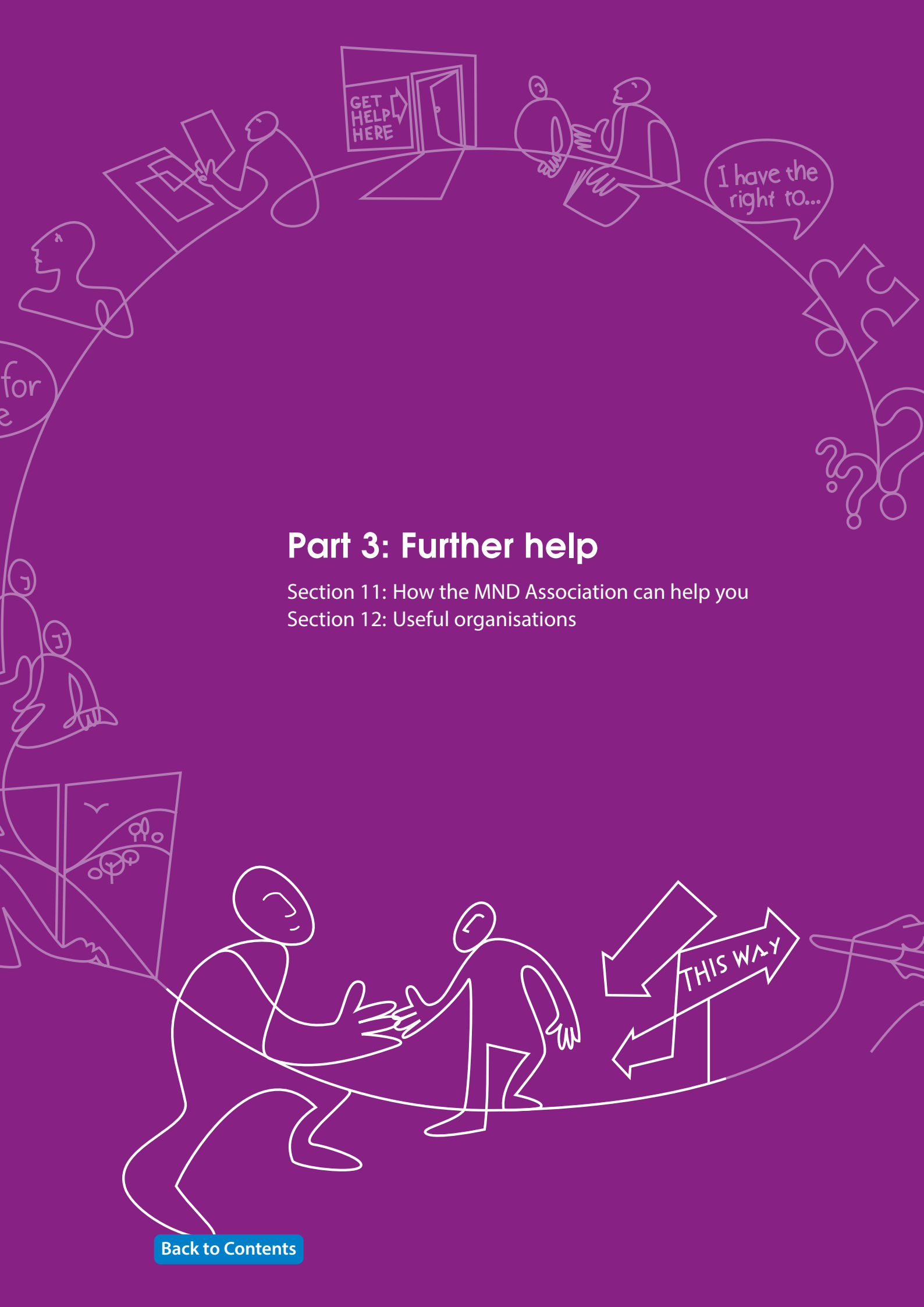
The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<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:

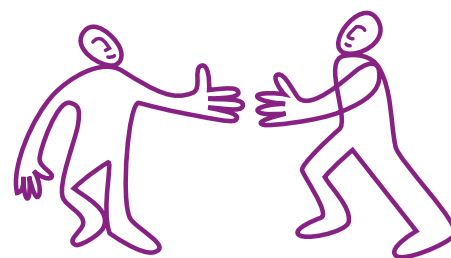
www.mndassociation.org/professionals



Part 3: Further help

Section 11: How the MND Association can help you
Section 12: Useful organisations

11: How the MND Association can help you



This section will help you access services and support from the MND Association.

What does the MND Association do?

We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. Scotland is supported by a different organisation called MND Scotland.

See [Section 12: Useful organisations for contact details](#).

Our overall vision is a world free from MND.

Our mission is to:

- improve care and support for people with MND, their families and carers
- fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND
- campaign and raise awareness, so the needs of people with MND and everyone who cares for them, are recognised and addressed by wider society.

The earlier we can help you, the more we can accomplish on your behalf. You may at times feel very isolated, but you are not alone in this.

How does the MND Association help carers?

In a caring role, you need to achieve the best possible quality of life for yourself and the person you support. This means access to appropriate services and information.

We work towards this goal by:

- building and improving our range of information for carers
- informing carers of available support, benefits and care options to enable greater choice and control
- providing local guidance through regional staff and volunteers
- enabling peer support through local branches and groups and our online forum
- providing MND Support Grants, Carers' Grants, a young person's grant and equipment loans as appropriate
- directing carers to opportunities for training in care tasks
- raising awareness about carers and the demands of MND within regional health and social care systems
- campaigning and influencing government and health and social care services.

We recognise the huge demands on you when you support someone with MND. You need specific support tailored to your individual and changing situation. We are constantly seeking ways to help you access appropriate services and to improve the support we provide.

MND Association services

The following headings list our services, with contact details.

MND Connect helpline

Our helpline provides support and information for people living with MND, their carers and families, our volunteers, and health and social care professionals.

If you are concerned about any aspect of care or how to manage the caring role, contact MND Connect.

The team can direct you to practical support, including our own services and appropriate external organisations. If you simply need to talk to someone, they can listen.

The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Benefits Advice Service

The MND Association Benefits Advice Service provides free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: **0808 801 0620**
(England & Wales)
0808 802 0020
(Northern Ireland)

Email: Through the website contact page, at:
www.mndassociation.org/benefitsadvice

Association visitors (AVs)

AVs are volunteers who provide free and confidential personal guidance to people with MND, their carers, and close family and friends. An AV can help you identify problems as they arise, answer questions and discuss how you might get support.

All AVs are carefully selected, undergo a thorough training programme and a Disclosure and Barring Service (DBS) check. They are based in the local community as members of a team and can make contact with you by phone, email or visiting you at home.

If you would like to be supported by an AV, contact our MND Connect helpline. Our regional staff can then put you in contact with an AV, where available.

If an AV is not available in your area, we can offer ongoing support and help through our helpline or your local branch or group. Please see other headings in this list for details of these services.

Regional staff for local support

Our regional staff for local support have knowledge about care for people with MND and how to support carers. They work with affected families, our volunteers and services. Their aim is to help ensure that appropriate care is made available at the right time.

Find out more about our services and local support at: www.mndassociation.org/support-and-information

Or contact our MND Connect helpline as shown in this section.

Local branches and support groups

We have a network of branches and groups across England, Wales and Northern Ireland. They provide a warm welcome, friendship and the opportunity to meet others affected by MND.

Our branches and groups offer guidance and support, including get-togethers and group meetings specifically for carers. People can share emotional and practical support, and exchange information.

Our branches are listed on our website at: www.mndassociation.org/branchesandgroups or contact our MND Connect helpline to help you find the nearest location:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND care centres and networks

We part-fund MND care centres and networks across the UK, with more planned. These offer specialist help to manage the complexity of the disease, supporting people with MND, their carers and families.

If you cannot get to a care centre or network easily, you and the person you support can still receive co-ordinated care through regional neurological services and local specialist palliative care services.

All of the care centres and networks bring together a range of health and social care professionals to provide co-ordinated care. They are usually referred to as a multi-disciplinary team.

Care centres are not a 'building' and usually take place in an established clinic in one place, such as a hospital. Networks work in a similar way, but do not have a fixed location, in order to provide a service across a wide geographical area.

Care centres and networks sometimes run clinical drug trials and undertake clinical research about MND. They also help to educate colleagues in the community and share good practice to improve MND care and support.

To find your nearest MND care centre or network see:

www.mndassociation.org/carecentres or contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

Equipment loan and grants

We may be able to provide certain items of equipment and communication aids on loan, or consider requests for financial support through grants.

All statutory funding and services should be explored first. However, loaned items can be provided if you have to wait for health and social care services to arrange equipment or if they are unable to provide an item.

The following types of grant are available:

MND support (care) grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided.

Application: by a health or social care professional following assessment of need, where this need cannot be met through the services they link to, or where provision will be delayed.

Can be used for: a variety of purposes, such as home adaptations, equipment or respite care.

MND quality of life grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided, up to £500 in any one grant.

Application: by any family member, Association visitor, health or social care professional or a regional care staff contact.

Can be used for: improving quality of life for the person diagnosed, or for equipment that does not require a health or social care assessment.

MND carer's and young carer's grant

Provided to: family or non-professional carers, who are 16 or older.

Amount provided: up to £500 is available in any one year.

Application: by the carer, or on their behalf by one of our Association visitors or a health and social care professional.

Can be used for: a break from caring, as with a pamper day, a short break or to support a hobby.

Young person's grant

Provided to: a child or young person aged 18 or under, who has a parent with MND or Kennedy's disease, or who lives in the same household with someone who has been diagnosed.

Amount provided: up to £250 is available in any one year.

Application: by a family member for the young person, or on their behalf by one of our Association visitors, a regional care staff contact or a health or social care professional.

Can be used for: a variety of purposes, such as decorating their room at home, a family day out or for equipment to help the young person, such as a laptop.

If you have any queries about grants or equipment loans, please contact our MND Connect helpline, as shown in this list.

Communication Aids Service

Help with queries about communication aids, for people with or affected by MND, and health and social care professionals.

A limited amount of financial support can be provided, and some items on loan (if unavailable or delayed through health and social care services).

Telephone: **0808 802 6262**

Email:

communicationaids@mndassociation.org

Our website

The MND Association makes every effort to ensure it provides trustworthy information (see *Care information and publications* heading). Please visit the MND Association website to find out more about MND, our services and the Association at:

www.mndassociation.org including news about our research, volunteering, fundraising and campaigning activities.

Our online forum

A safe place to share experiences and tips with others affected by MND.

Access the forum on our website, or at:
https://forum.mndassociation.org

Care information and publications

We provide a wide range of information, developed and revised under the PIF Tick kitemark scheme: **https://piftick.org.uk**

This means our content is considered trustworthy. Look for the following kitemark:



Patient Information Forum

You can download the majority of our care information from our website, including our publications list, using the following address:
www.mndassociation.org/publications

Or contact MND Connect to order printed copies (see previous *MND Connect helpline* heading).

Membership

Membership of the MND Association enables you to join a community of people living with MND, their spouses, partners and carers. It enables you to join a community of people who all share the same vision of a world free from MND. As a unified force, our membership creates a powerful voice to support lobbying and campaigns on behalf of all people affected by MND.

By becoming a member, you will:

- have opportunities to influence the work of the Association
- be sent a welcome pack, including membership card
- be able to link to your nearest branch or group.
- receive Thumb Print, our Quarterly magazine
- be able to attend and vote at our AGMs
- have invitations to our conferences and events
- have access to a collectible pin badge every year.

To become a member, contact us by:

Telephone: **01604 611860**

Email: **membership@mndassociation.org**

Support for everyone and other languages

We are here for everyone living with or affected by MND.

We are aware that not everyone will have the same needs, as everyone's experience of MND will be unique. Culture and religion may also influence the way care and support should be provided and the MND Association supports diversity and equality in all of its services.

Please ask the service you are dealing with if you have any particular preferences or needs that you wish to be taken into consideration.

We offer a limited translation service for our health and social care information, other formats and telephone interpreters. Contact our MND Connect helpline for details (see previous heading *MND Connect Helpline*).

Getting involved

Many people with or affected by MND or Kennedy's disease ask how they can get involved with our activities. If you would like to know more, see the following web pages:

Volunteering:

www.mndassociation.org/volunteering

Fundraising:

www.mndassociation.org/fundraising

Campaigning:

www.mndassociation.org/campaigning

Research:

www.mndassociation.org/research

Or contact enquiries:

Telephone: **01604 250505**

Email: **enquiries@mndassociation.org**

Key points

- We support everyone with or affected by MND or Kennedy’s disease in England, Wales and Northern Ireland (support is provided in Scotland by MND Scotland).
- Our services are free for people with MND or Kennedy’s disease, their partners and carers.
- If you need assistance to contact any of our services or external services, contact our MND Connect helpline:

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

12: Useful organisations



This section will help you identify some of the organisations that provide carers with further information or support.

The organisations listed here have been split into two groups to help you find appropriate support:

1: Organisations for adult carers

These services may also help young carers, but their main focus is support for adult carers or related services that adult carers might use.

2: Organisations for children, young people and young carers

These services are aimed specifically at children and young people.

You can access a wider list of useful organisations on our website at: www.mndassociation.org/support-and-information and we list relevant organisations at the end of all our information sheets.

Your local authority or, in Northern Ireland, your local health and social care trust, can direct you to regional providers and may offer a directory of services on their website.

See our [Contact record in Part 4 of this guide to keep details for regular contacts](#).

We do not necessarily endorse the organisations listed here and cannot be held responsible for anything stated on their website or supplied as a service or a product.

We keep this information updated, but details may change between revisions. If you need help locating an organisation, contact our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

The helpline team can also direct you to our services and local support.

Organisations that can help adult carers

Advicenow

Online information on rights and legal issues.

Website: www.advicenow.org.uk

Age UK

Information, advice and advocacy for people in later life, including guidance on benefits.

Age UK, Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: **0800 678 1602**

Email: through website contact page

Website: www.ageuk.org.uk

Alzheimer's Society (AS)

For information about supporting someone with cognitive impairment or dementia.

Alzheimer's Society, Scott Lodge, Scott Road, Plymouth, PL2 3DU

Telephone: **0330 333 0804**

Email: through website contact page

Website: www.alzheimers.org.uk

Asian Health Agency

Information and support for Asian elders, disabled people and carers across the UK, with care services across many London boroughs.

Email: through the website contact page

Website: www.taha.org.uk

BackCare

Information and advice on back pain and manual handling.

BackCare, Monkey Puzzle House,
69-71 Windmill Road, Sunbury-on-Thames
TW16 7DT

Telephone: **0208 977 5474**

Email: **info@backcare.org.uk**

Website: **www.backcare.org.uk**

Bereavement Advice Centre

Information about the legal and practical steps to take after someone's death, including a booklet called *What to do when someone dies*, a practical guide.

Bereavement Advice Centre, 1 Angel Square,
Manchester, M60 0AG

Freephone: **0800 634 9494**

Website: **www.bereavementadvice.org**

Blue Badge Scheme

A blue badge enables access to a range of parking benefits and other motoring concessions for people with severe mobility difficulties. Contact your local authority or look online at GOV.UK

Website: search for *blue badge* at:

www.gov.uk or in Northern Ireland at:

www.nidirect.gov.uk

BME Health Forum

An organisation helping to improve health services for black and minority ethnic groups. Their work is based in London, but their site includes patient information on rights for healthcare and how to access support.

BME Health Forum, Church Street
Neighbourhood Centre, Cherwell House,
Penfold Street, London NW8 8PT

Email: through website contact page

Website: **www.bmehf.org.uk**

British Red Cross

For health and social care assistance, equipment hire (eg standard wheelchairs) and various disability living aids for purchase.

British Red Cross, 44 Moorfields,
London EC2Y 9AL

Telephone: **0344 871 11 11**

Email: **contactus@redcross.org.uk**

Website: **www.redcross.org.uk**

Care Quality Commission (CQC)

Use the search facility to locate a care service in England, such as a nursing care home, to read the ratings from the last inspection. Contact the CQC if you are concerned about the care received from a provider in England.

Telephone: **03000 616161**

Email: **enquiries@cqc.org.uk**

Website: **www.cqc.org.uk**

Care Inspectorate Wales

Use the search facility to locate a care service in Wales, such as a nursing care home, to read the ratings from the last inspection. Contact the CSSIW if you are concerned about care received from a provider in Wales.

Welsh Government office, Sarn Mynach,
Llandudno Junction LL31 9RZ

Telephone: **0300 7900 126**

Email: through the website contact page

Website: **https://careinspectorate.wales**

Carer's Allowance Unit

For queries about Carer's Allowance.

Telephone: **0800 731 0297**

Website: search for *carers allowance* at:

www.gov.uk (includes online claim submission)

Northern Ireland:

Telephone: **0800 587 0912**

Website: search for *Carer's Allowance* at

www.nidirect.gov.uk/articles/carers-allowance

Carers Trust

Support for carers.

Carers Trust, Unit 101, 164-180 Union Street,
London SE1 0LH

Telephone: **0300 772 9600** (England)

0300 772 9702 (Wales)

028 3026 7015

(Northern Ireland)

Email: **info@carers.org** (England)

wales@carers.org (Wales)

info@carers-nm.org

(Northern Ireland)

Website: **https://carers.org**

Carers UK

Information, advice and campaigning for the
rights of carers.

Carers UK, 20 Great Dover Street,
London SE1 4LX

Telephone: **0808 808 7777**

Email: through the website contact page

Website: **www.carersuk.org**

Chinese National Healthy Living Centre

Advice on health issues for people in the
Chinese Community, including support
for carers.

Chinese National Healthy Living Centre,
29-30 Soho Square, London W1D 3QS

Telephone: **020 3802 0350**

Email: **info@cnhlc.org.uk**

Website: **www.cnhlc.org.uk**

Citizens Advice Bureau

Free information and advice on legal, money
and other problems. Contact your local
bureau for support – you can search for your
local branch on their website.

Telephone:

0800 144 8848 (for England or contact your
local branch)

0800 702 2020 (for Wales)

Website: **www.citizensadvice.org.uk**

Community Law Service

Independent advice and representation,
including welfare benefits, debt and housing.
Contact your local service by searching for
community law service online.

Cruse Bereavement Care

Face-to-face bereavement support is
available through local branches across
England, Wales and Northern Ireland, with
a helpline and e-mail service for adults and
young people.

Cruse Bereavement Care, Unit 0.1,
One Victoria Villas, Richmond, TW9 2GW

Helpline: **0808 808 1677**

Website: **www.cruse.org.uk**

Disability Law Service

Contact the DLS for assistance on
disability law.

Disability Law Service, The Foundry,
17 Oval Way, London, SE11 5RR

Telephone: **020 7791 9800**

Email: **advice@dls.org.uk**

Website: **www.dls.org.uk**

Disability Rights UK

Information, products and services designed
by and for disabled people.

Disability Rights UK, Plexal, 14 East Bay Lane,
Here East, Queen Elizabeth Olympic Park,
Stratford, London E20 3BS

Telephone: **0330 995 0400**

Email: **enquiries@disabilityrightsuk.org**

Website: **www.disabilityrightsuk.org**

Elderly Accommodation Counsel (EAC)

National register of all types of accommodation to help the elderly make informed choices about their housing and care needs.

EAC, Suite A, 202 Lambeth Road,
London SE1 7JW

Email: through website contact page

Website: www.eac.org.uk

GOV.UK

Online government information about financial help and benefits.

Website: www.gov.uk
(England and Wales)
www.nidirect.gov.uk
(Northern Ireland)

Health in Wales

Online information about NHS services in Wales including a directory of the Welsh health boards. (See also NHS Direct Wales).

Email: through the website contact page

Website: www.wales.nhs.uk

Health Professions Council (HPC)

A register of health professionals who meet HPC standards of practice, with a search facility to find professionals, including psychologists, physiotherapists, occupational therapists and speech and language therapists.

Health Professions Council, Park House,
184 Kennington Park Road, London SE11 4BU

Telephone: **0300 500 6184**

Website: www.hpc-uk.org

Healthtalk.org

A website of personal health experiences, including a series of interviews with people affected by or living with MND.

Website: search for *motor neurone disease* at:
www.healthtalk.org

Hospice UK

Information on hospices and hospice care across the UK.

Hospice UK, 34-44 Britannia Street,
London WC1X 9JG

Telephone: **020 7520 8200**

Email: through website contact page

Website: www.hospiceuk.org

Independent Age

Independent advice on a range of care issues, including care assessments, getting help at home, paying for care, benefits and hospital discharge.

Independent Age, 18 Avonmore Road,
London W14 8RR

Telephone: **0800 319 6789**

Email: advice@independentage.org

Website: www.independentage.org

Jobcentre Plus

Contact your local Jobcentre Plus for advice about employment and some benefit claims. Search for your local office through the website.

Telephone: **0800 169 0190**

Textphone: **0800 169 0314**

Email: through website contact page

Website: search for either *employment* or *jobcentre plus* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

LGBT Foundation

Information and advice for lesbian, gay and bisexual people, including carer support.

LGBT Foundation, PO Box 5577,
Manchester M61 0TT

Telephone: **0345 3 30 30 30**

Email: info@lgbt.foundation

Website: <https://lgbt.foundation>

Lions Clubs International (British Isles and Ireland)

A community service organisation, helping to promote the Message in a Bottle scheme to assist paramedics in case of emergencies.

Lions Clubs International, 257 Alcester Road South, Kings Heath, Birmingham B14 6DT

Telephone: **0121 441 4544**

Email: **enquiries@lionsclubs.co**

Website: **<https://lionsclubs.co/Public>**

Living made easy

Previously the Disabled Living Foundation. Provides guidance on aids for disabled people.

Telephone: **0300 999 0004**

Email: **info@dlf.org.uk**

Website: **<https://livingmadeeasy.org.uk>**

Medic Alert

An identification system for individuals with medical conditions, usually in the form of bracelets or necklets, supported by a 24 hour emergency telephone service.

MedicAlert, Suite 1, Liscombe South, Liscombe Park, Soulbury, LU7 0JL

Telephone: **01908 951045**

Email: **info@medicalert.org.uk**

Website: **www.medicalert.org.uk**

Motability

For details about vehicle leasing or hire purchase through the Motability scheme.

Telephone: **0300 456 4566**

Email: through website contact page

Website: **www.motability.co.uk**

MND Scotland

Support for people affected by MND in Scotland.

MND Scotland, Unit 8, 76 Firhill Road, Glasgow G20 7BA

Telephone: **0141 332 3903**

Email: **info@mndscotland.org.uk**

Website: **www.mndscotland.org.uk**

National Debtline

An independent confidential helpline offering free advice about debt problems in England, Wales and Scotland.

National Debtline, Tricorn House, 51-53 Hagley Road, Edgbaston, Birmingham B16 8TP

Telephone: **0808 808 4000**

Email: through website contact page

Website: **www.nationaldebtline.org**

NHS UK

Online health information from the NHS.

Telephone: **111**

Email: through the website contact page

Website: **www.nhs.uk**

NHS 111

The NHS online/telephone help and support for urgent (but not emergency) health advice and information, 24-hours a day, 365 days a year.

Telephone: **111**

Email: through the website contact page

Website: search for *NHS 111* at: **www.nhs.uk**

NHS 111 Wales

Similar to NHS 111, but for medical advice in Wales.

Telephone: **111 (0845 46 47 in some areas)**

Website: <https://111.wales.nhs.uk/>

NHS Northern Ireland

Online information for the NHS in Northern Ireland.

Email: through the website contact page

Website: <http://online.hscni.net>

The Office of Care and Protection

The organisation that handles applications for Enduring Power of Attorney (EPA) in Northern Ireland.

Office of Care and Protection, Room 2.2A, Second Floor, Royal Courts of Justice, Chichester Street, Belfast BT1 3JF

Telephone: **0300 200 7812**

Email: OCP@courtsni.gov.uk

Website: search for *enduring power of attorney* at: www.nidirect.gov.uk

Office of the Public Guardian

The organisation that handles applications for Lasting Power of Attorney (LPA) in England and Wales.

Office of the Public Guardian, PO Box 16185, Birmingham B2 2WH

Telephone: **0300 456 0300**

Email:

customerservices@publicguardian.gov.uk

Website: search for *office of the public guardian* at: www.gov.uk

Outsiders Trust

Support on relationships and sexuality for people affected by disabilities, including advice to help health and social care professionals provide better guidance.

Outsiders Trust, WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE

Telephone: **07872 681 982**

Email: info@outsiders.org.uk

Website: <https://outsiders.org.uk>

The Patient Advice and Liaison Service (PALS)

PALS is a local service at all NHS Trusts in England, providing confidential advice to families and carers about NHS and health matters.

Telephone: contact your local hospital, GP or health clinic

Website: Search for *PALS* at: www.nhs.uk

For Northern Ireland:

Patient and Client Council

Freephone: **0800 917 0222**

Email: info.pcc@pcc-ni.net

Website: www.patientclientcouncil.hscni.net

For Wales:

Please refer to your local Community Health Council.

Website: search for *community health councils* at: www.wales.nhs.uk

Pension Service

For queries and claims regarding pensions and pension credit.

Telephone: **0800 731 7898**

Textphone: **0800 731 7339**

Website: search for *pensions* at: www.gov.uk

For Northern Ireland:

www.nidirect.gov.uk

The Regulation and Quality Improvement Authority (RQIA)

Use the search facility to locate a care service in Northern Ireland, such as a nursing care home. You can then read the ratings from the most recent inspection. Contact the RQIA if you are concerned about the care received from a provider in Northern Ireland.

RQIA, 7th Floor Victoria House,
15-27 Gloucester Street, Belfast, BT1 4LS

Telephone: **028 9536 1111**

E-mail: **info@rqia.org.uk**

Website: **www.rqia.org.uk**

Relatives & Residents Association

For advice about moving to a residential or nursing home if you are older and need care.

Relatives and Residents Association, Unit 6,
Aztec Row, 1 Berners Road, London N1 0PW

Telephone: **020 7359 8136**

Email: **helpline@relres.org**

Website: **www.relres.org**

Ricability

Free, unbiased reports for people with disabilities, based on consumer research.

Ricability, Ground floor, Unit 10,
Blenheim Court, 62 Brewery Road,
London N7 9NY

Telephone: **020 7427 2460**

Email: **mail@ridc.org.uk**

Website: **www.ricability.org.uk**

The Royal Association for Deaf People

For information, support and advice if your first language is British Sign Language.

The Royal Association for Deaf People,
Block F, Parkside Office Village, Knowledge
Gateway, Nesfield Road, Colchester CO4 3ZL

Telephone: **0300 688 2525**

Textphone: **0300 688 2527**

SMS: **07851 423 866**

Email: **info@royaldeaf.org.uk**

Website: **www.royaldeaf.org.uk**

The Royal National Institute of Blind People (RNIB)

For information, support and advice if you are affected by sight loss.

RNIB, 105 Judd Street, London WC1H 9NE

Helpline: **0303 123 9999**

Email: **helpline@rnib.org.uk**

Website: **www.rnib.org.uk**

Samaritans

Confidential 24-hour emotional support for people experiencing feelings of distress or despair. Their service is available by telephone, email, letter or face-to-face in most branches.

Write to: Freepost SAMARITANS LETTERS

Telephone: **116 123** (or contact your local branch)

Email: **jo@samaritans.org**

Website: **www.samaritans.org**

Shopmobility

A scheme in many towns and shopping centres, providing manual or powered wheelchairs or scooters, for loan or hire.

ShopMobility UK, c/o Driving Mobility,
The Old Carriage Works, Moresk Road,
Truro TR1 1DG

Email: through website contact page

Website: **https://shopmobilityuk.org**

Social Services

Contact your local authority if you need to speak to someone in social services or book a carer's assessment. For Northern Ireland, search for *Health and Social Care Trusts* at **www.nidirect.gov.uk**

Step Change Debt Charity (Consumer Credit Counselling Service)

Free and confidential advice on debt management.

StepChange Debt Charity, 123 Albion Street,
Leeds LS2 8ER

Telephone: **0800 138 1111** (helpline)

Email: through the website contact page

Website: **www.stepchange.org**

Way Widowed and Young

Supporting people under the age of 50 who have been widowed.

WAY Widowed and Young, Suite 14,
College Business Centre, Uttoxeter New Road,
Derby DE22 3WZ

Email: through website contact page

Website: **www.widowedandyoung.org.uk**

Turn2us

Help to find out available benefits, grants, financial support or funding.

Website: **www.turn2us.org.uk**

Working Families

Helping parents, carers and employers find a better balance between work and home.

Working Families, c/o Buzzacott LLP,
130 Wood Street, London EC2V 6DL

Helpline: **0300 012 0312**

Email: through website contact page

Website: **www.workingfamilies.org.uk**

Organisations that can help children and young people

Action for Children

Help for vulnerable children and young people, including young carers.

Action for Children, 3 The Boulevard,
Ascot Road, Watford WD18 8AG

Telephone: **0300 123 2112**

Email: **ask.us@actionforchildren.org.uk**

Website: **www.actionforchildren.org.uk**
(search for young carers)

Barnardo's

A charity supporting children across the UK, including services for young carers.

Barnardo's, Tanners Lane, Barkingside,
Ilford, Essex IG6 1QG

Telephone: **0800 008 7005** (England)

029 2049 3387 (Wales)

028 9067 2366

(Northern Ireland)

Email: through the website contact page

Website: search for young carers at:

www.barnardos.org.uk

Bullying UK

Help on bullying issues, with advice for children and young people. You can find your local office on their website.

Telephone: **0808 800 2222**

(confidential helpline)

Email: through the website contact page

Website: **www.bullying.co.uk/advice**

Child and adolescent mental health services (CAMHS)

Specialist NHS children and young people's mental health services, offering assessment and treatment when children find it emotionally hard to cope with daily life. If family, friends or GPs are unable to provide the necessary support, CAMHS may be able to assist. The child will need to be referred by a professional – ask your GP or the child's school for assistance. You can search online for *Child and adolescent mental health services* in your area or on your local NHS trust website.

Child Bereavement Charity

Support for families, children and young people during bereavement.

Child Bereavement UK, Unit B Knaves
Beech Way, Knaves Beech Industrial Estate,
Loudwater, High Wycombe, Bucks HP10 9QY

Telephone: **0800 0288840**

Email: **helpline@childbereavementuk.org**

Website: **www.childbereavementuk.org**

Childhood Bereavement Network

Support for bereaved children, young people and their families across the UK.

Email: **cbn@ncb.org.uk**

Website: **www.childhoodbereavementnetwork.org.uk**

Childline

Counselling and a free 24-hour helpline for children or young people in distress or danger.

Childline, Via NSPCC, Weston House,
42 Curtain Road, London EC2A 3NH

Telephone: **0800 1111**

Email: through website and confidential login
(does not require your real name)

Website: **www.childline.org.uk**

The Children's Society

Support and services for children and young carers. The website includes details about the annual Young Carer Festival.

The Children's Society, Whitecross Studios,
50 Banner Street, London EC1Y 8ST

Telephone: **0300 303 7000**

Email: through the website contact page

Website: **www.childrenssociety.org.uk**

The Children's Society – Include Programme

Support and services for young carers, including details about the annual Young Carer Festival.

Telephone: **01962 711511**

Email: through the website contact page

Website: **www.youngcarer.com**

Winston's Wish

Support for bereaved children, young people and their families.

Winston's Wish, 3rd Floor, Cheltenham House,
Clarence Street, Cheltenham GL50 3JR

Helpline: **08088 020 021**

Email: **ask@winstonswish.org**

Website: **www.winstonswish.org.uk**

Young Minds

Information and support for emotional wellbeing and mental health, for children and young people. They may be able to provide guidance if you are waiting to see CAMHS.

Telephone: **0808 802 5544**

Textline: text **YM** to **85258** for free,
24/7 support

Website: **www.youngminds.org.uk**

Youth Access

A national membership organisation for young people's information, advice, counselling and support services.

Youth Access, 1-2 Taylors Yard,
67 Alderbrook Road, London SW12 8AD

Telephone: **020 8772 9900**

Email: **admin@youthaccess.org.uk**

Website: **www.youthaccess.org.uk**

Part 4: Keeping notes

This part of the guide includes the following write-on pages, to help you keep important records:

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You can order additional copies from our MND connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Or you can download and print copies at:

www.mndassociation.org/carerguide



Care summary

Keeping notes about the care tasks you do, can provide useful evidence for appointments or assessments with health and social care professionals.

You can use this *Care summary* to record your notes. It may help to mark tasks in your diary for a week or two. This will show how often you do things and how long they take. See the examples below:

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
	12th January 2022		
Collecting prescriptions and medication	Once a month, but can take an hour to make the round trip and I hate leaving my husband on his own for this long		
Administering medication	Five times a day and can take up to five minutes each time, due to swallowing difficulties		

You only need to make notes against tasks that are relevant to the care of the person you support and you can add further tasks at the bottom of the summary table if necessary.

Add a date to the top of the column you are completing, as this will help you remember when you recorded the information. Use subsequent columns at later intervals to help track any increase in the levels of care over time.

Please see the following page for the full *Care summary*.

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Food preparation or cooking			
Housework			
Laundry			
Shopping			
Physical care <i>(such as helping the person get up from a chair or go upstairs)</i>			
Contacting, visiting or checking on the person <i>(to ensure they are safe and well)</i>			
Personal care <i>(such as dressing, washing, helping with toileting needs)</i>			
Overnight or night-time care			

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Administration for benefits or financial support			
Collecting prescriptions and medication			
Administering medication			
Assisting with medical or complementary treatments when appropriate			
Providing emotional support			
Assisting communication <i>(for speech impairment, hearing loss or if English is not the first language)</i>			
Arranging appointments or accompanying at appointments			
Driving or accompanying on travel			

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Assisting with leisure activities <i>(such as hobbies, interests, entertainment, etc)</i>			
Helping to contact services and support organisations			
Gardening			
House maintenance			
Looking after visitors			
Other task:			
Other task:			
Other task:			

Carer's assessment preparation

This item shows the typical questions that may be asked at a carer's assessment. The way you use this tool is entirely up to you. You may simply want to look at the questions before the assessment to think about your responses, or make notes to ensure you include key points. You may need extra paper if some of your responses need more detail.

There is a lot to consider and we have included as many prompts as possible to help prepare you. You may find just a few prompts are relevant, or all of them. Please note, the actual questions asked at the full assessment may vary between local authorities.

You may also wish to use other tools in this toolkit at your carer's assessment, such as the *Care summary*, to support and clarify your needs. You may find the *Care summary* helps at assessment too, also in Part 4 of this guide.

General information:

What is your relationship to the person you are caring for?

What is the nature of the cared for person's illness or disability?

What is your GP's name?

What are your GP's contact details?

What is your ethnic origin?

(Ethnic origin may be important in terms of accessing other services such as interpreters)

What is the ethnic origin of the person you are caring for?

(Ethnic origin may be important in terms of accessing other services such as interpreters)

Do you have any personal communication needs or wish to communicate in a preferred language?

Do you have any cultural or spiritual needs that need to be taken into consideration?

Do you have any personal health concerns? *(such as illness or physical impairment)*

General information: *(continued)*

Do you have any other commitments? For example:

Paid work Family, eg children Study or training Voluntary work Other

How long have you been a carer?

How many hours per week do you spend caring?

Are you willing and able to continue caring?

Other people in your household:

Who else lives in your household?

What is their relationship?

Are they involved in the care duties?

Their age if under 18?

Do you have any other comments concerning the impact on other people in your household?

Practical tasks:

Notes on level of care/input required:

Shopping

Laundry

Housework

Cooking

Correspondence

Administration/finance

What kind of support would help you with the above?

Personal care tasks:*Notes on level of care/input required:*

Assisting with getting dressed

Assisting with eating/drinking

Assisting with toileting

Bathing and personal hygiene

Support during the night

What kind of support would help you with the above?

Tasks concerning getting around:*Notes on level of care/input required:*

Providing transport

Arranging transport

Assistance when travelling

What kind of support would help you with the above?

Tasks concerning personal mobility:*Notes on level of care/input required:*

Getting in and out of bed

Getting in and out of chairs

Getting in and out of shower/bath

Getting in and out of transport

Help using the toilet/commode

Assisting with exercise

Moving around

What kind of support would help you with the above?

Tasks concerning health:

Notes on level of care/input required:

Visits to GP/care centre/hospital

Visits to GP/care centre/hospital

Collecting medication

Medication giving or monitoring

Controlling medical equipment (*eg tube feeding*)

Breathing and respiratory issues

Urgent or emergency situations (*such as falls*)

Other health needs

What kind of support would help you with the above?

Tasks concerning communication:

Notes on level of care/input required:

Support with socialising

Advocating (*asking services for advice or support*)

Interpreting (*with language or speech impairment*)

What kind of support would help you with the above?

Other issues experienced by the person you care for, that you deal with:

Notes on level of care/input required:

Mood swings/behaviour change

Lack of sleep or fatigue

Anxiety/fearfulness

Changes to thinking or reasoning

Difficulty with interests/hobbies

Financial hardship

Safety indoors/outdoors

Strain on your relationship

Strain on family/close friends

Maintaining social life

Housing adaptations

Other accommodation issues

Discrimination due to disabilities

What kind of support would help you with the above?

Other things to consider:

What problems and difficulties do you have as a carer?

What extra support would improve your quality of life or make life easier?

Would you like access to lists of care workers and services in the local area?
(This may be particularly important if either you or the person you are caring for decide to accept direct payments for social care or health care.)

Would you like access to a list of carer support groups and any local carer centres?

Would you like information on how to handle emergencies and who to contact?

Would you like a plan of action in place in case you need to be absent?
(eg you need hospital treatment.)

Would you like access to any other specific information or advice?

Do you need assistance with legal issues, such as Power of Attorney or making a will?

Are you likely to need respite care, or carer breaks, now or in the future?

Is there anything else that should be known regarding your caring role or personal situation?

How do you feel a full carer's assessment might be able to help you and what would you like this to do for you?

Would you like the carer's assessment to be conducted privately? (You can have a joint needs assessment with the person you support, if wished.)

Appointment queries

Both you and the person you support can use this notes page, or a copy, for appointments with health and social care professionals. It can help you prepare and group questions for suggested areas of concern.

You can use the notes area to record the responses of the health or social care professional. You may wish to use this as a guide only and create your own version, or use extra paper to record any notes.

Appointment with:

Date:

Area of concern	Questions	Notes
Symptom control, medication or treatments:	For example: <i>My wife has a very dry mouth, is there anything that can help?</i>	
Specialist equipment or medical equipment:		
Speech and communication:		
Personal mobility:		

Area of concern	Questions	Notes
Difficulties performing practical tasks and personal care needs:		
Difficulties with eating and swallowing		
Emotional issues and impact on personal relationships:		
Changes to thinking or behaviour:		
Financial issues:		
Housing issues or adaptations:		

Area of concern	Questions	Notes
Carer support and respite care:		
How to get further advice and information:		

Other things to consider:

Contact record

You may find you need to communicate with a wide range of people, services and organisations when supporting someone with MND. Keeping contact details together may help you save time. We have included telephone numbers and email addresses where possible, but you will need to add details for local contacts.

MND Association services

Name or organisation	Contact details	Dates contacted	Notes
MND Connect helpline	0808 802 6262 mndconnect@mndassociation.org		
Young Connect helpline	0808 802 6262 youngconnect@mndassociation.org		
Association visitor			
MND Association branch or group			
Regional care development adviser			
Support services <i>(for equipment loans, MND Support Grants, Carer Grants and the Young Person's Grant</i>	0808 802 6262 or 01604 611802 supportservices@mndassociation.org		

MND Association services

Name or organisation	Contact details	Dates contacted	Notes
MND Association switchboard	01604 250505 enquiries@ mndassociation.org		
MND Association membership	01604 611860 membership@ mndassociation.org		
MND Association information feedback	infofeedback@ mndassociation.org		
MND Association online forum	https://forum.mndassociation.org		
MND Association website	www.mndassociation.org		
MND Association publications	www.mndassociation.org/publications or contact the MND Connect helpline (see earlier in list)		

Medical contacts:

Name or organisation	Contact details	Dates contacted	Notes
MND care centre or network			
Consultant			
GP			
District nurse			
MND specialist nurse			
Palliative care nurse			
Occupational therapist (OT)			
Speech and language therapist (SLT)			

Medical contacts: (continued)

Name or organisation	Contact details	Dates contacted	Notes
Physiotherapist			
Dietitian			
Pharmacist			
Counsellor			
Psychologist			
NHS 111	Call 111 if medical help is needed fast, but it is not a 999 emergency.		

Social care and related services:

Name or organisation	Contact details	Dates contacted	Notes
Social services (local)			
Local authority main switchboard			
Wheelchair service (local)			
Jobcentre Plus (local branch)			
Carer's Allowance Unit	0800 731 0297 www.gov.uk/carers-allowance-unit		
Citizens Advice Bureau (local branch)			
The Pension Service	0800 731 7898 www.gov.uk/contact-pension-service		
Religious or spiritual guidance			

Social care and related services: (continued)

Name or organisation	Contact details	Dates contacted	Notes

Other contacts and organisations:

Name or organisation	Contact details	Dates contacted	Notes

Acknowledgements

Our thanks to the following...

For sharing their experiences:

The many carers affected by MND who have provided feedback to the MND Association and helped to review the content of this guide. Their insight has been essential.

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Gabrielle Tilley, Community Education and Development Manager,
Great Western Hospitals NHS Foundation Trust, Chippenham

Sonja Woodhouse, Commissioning Manager Carers Lead, Northamptonshire County Council

References

References used to support this information are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information Feedback at the address on the following page.

We welcome your views

If you would like to provide feedback about *Caring and MND: support for you*, please use our online form at: www.smartsurvey.co.uk/s/carerguide or complete the enclosed feedback form.

Your feedback is really important, as it helps us develop new materials and improve our existing information. This helps other people living with or affected by MND. Thank you.

You can also email: infofeedback@mndassociation.org

Or write to:

Information Feedback using the address shown below on this page.

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Motor Neurone Disease Association
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Moulton Park, Northampton NN3 6BJ

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