

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.

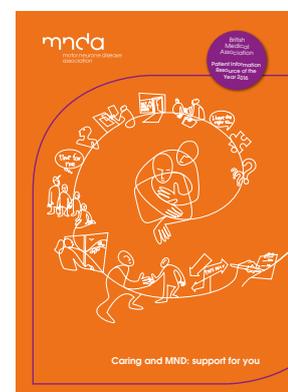
The following information is a section from our full guide *Caring and MND: support for you*.

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

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

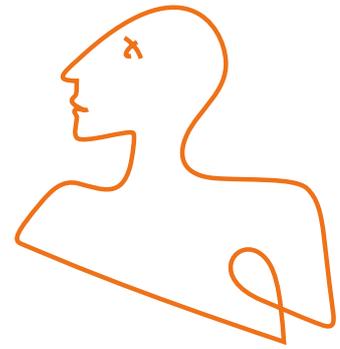
Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Caring and MND:
support for you**

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:

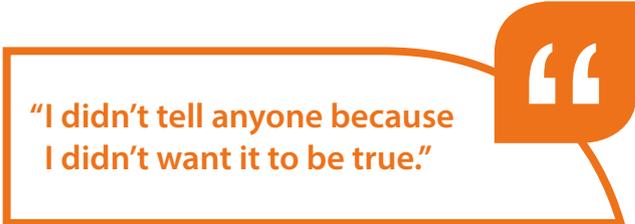
- sadness can reflect the depth of feeling you feel for someone
- guilt indicates that you care about what is happening around you
- anger can be a healthy response that enables positive action.

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.

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

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

How to access publications and further information:

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and regional staff.

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

Online forum:

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

<https://forum.mndassociation.org>

Information for professionals

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

www.mndassociation.org/professionals

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For references and acknowledgements
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from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

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



Patient Information Forum