

4: Emotional impact

This section will help you identify and manage emotional responses you may feel following diagnosis.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: **www.mndassociation.org/publications**

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

Telephone: **0808 802 6262**

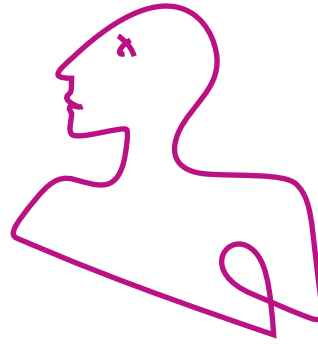
Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

4: Emotional impact

This section will help you identify and manage emotional responses you may feel following diagnosis.



Your emotions will be influenced by your own situation, culture and beliefs. Whatever responses you feel in the weeks and months following diagnosis, you are not alone. Seek help and support, in a way that works for you.

Expected reactions

For most, the diagnosis of MND comes as a shock and it's natural to feel distress. For some there is a sense of relief in finally getting an answer. Once you know what is happening, you can find appropriate support when needed.

As you adjust to diagnosis and what this means, your emotional responses may feel confusing.

“ I find myself wondering about my own identity. I feel as though I'm in conflict with another individual inside me, but not part of me.

Feelings can be mixed, as you can experience more than one distinct emotion at a time, such as anger and guilt.

You may experience:

- shock
- intense sadness
- fear for the future
- disbelief and denial
- anxiety for family, children and friends
- grief for the loss of the future you expected

- guilt that you may be the cause of stress for others
- anger at the medical profession, or family and friends
- isolation because you suddenly feel different from others
- relief that you finally know what is happening to you.

Feeling overwhelmed

First, give yourself permission to be emotional. A diagnosis of MND is not easy to hear, so work through your feelings at your own pace. You may need time to adjust before seeking support or information, but at some point you may wish to review your life and plans.

It can be difficult to find a positive approach when facing such a challenge. You may feel determined to face the disease head on and fight it, or you may prefer to deal with it one day at a time.

“ I've only just started to accept my condition and read more...For a long time I believed it would go away or that I'd been wrongly diagnosed.”

Learning to accept that you have a life-shortening disease is not easy. You may even find that family and friends seek information and support services before you do. They will have their own questions about what is happening and taking action can help them adjust.

When you feel ready, discussing your feelings with those close to you is vital. MND affects them too, and sharing highs and lows means you can support each other.

See Section 5: Family, children and friends for help on managing conversations about MND.

We also have resources for family, carers and friends. While there are ways to prolong your independence, you will need more help over time. Our resources for carers include emotional guidance to support their wellbeing too.

See Further information at the end of this section, about resources for carers and our guide, *Telling people about MND*.

Emotional lability

You may find you laugh or cry at inappropriate times. This can be difficult to stop and hard for others to understand. If it happens, it may feel distressing for yourself and those close to you.

“ It doesn’t help when people say things like ‘Get control of yourself’. The more I try to do that, the harder it gets. It feels as though something is using my body against my will.”

Known as emotional lability (also pseudobulbar affect), this symptom can happen with MND, but is not experienced by everyone with the disease.

Despite the way it makes you feel, emotional lability is a physical reaction rather than emotional. It’s an abnormal motor response, which can be caused by MND. The disease affects the pathway between the outer layer of the brain and the brain stem, resulting in emotional responses that don’t always match how you feel. For example, you may laugh uncontrollably when you feel sad, or you may cry when you feel happy.

This symptom usually reduces over time. Understanding the cause can help you and your family adjust, and manage the impact.

“ I have an advice sheet with me that I can give to people if I break down, as when this happens I cannot speak or communicate.”

If emotional lability is severe and begins to limit what you do, medication or therapy may help. Ask your GP for advice. If they are not familiar with emotional lability, ask for referral to a specialist with experience of neurological conditions.

Some people with MND experience changes to thinking and behaviour (called cognitive change). In these instances, it’s more common to experience emotional lability. However, emotional lability is not in itself a sign of changes to thinking.

See Section 2: *Managing symptoms* for more detail on changes to thinking and behaviour.

Depression

With any serious illness, low moods are to be expected at times. If you find it difficult to recover from these lows, it may be time to seek some help. Watch for physical signs, such as:

- difficulty sleeping
- loss of interest
- loss of appetite
- lack of energy.

These can be signs of other symptoms, rather than depression, so ask your health care team for guidance. Discuss any ongoing distress, including:

- feelings of hopelessness
- sadness that you cannot shake off
- loss of interest in activity
- difficulty finding pleasure or enjoyment in anything
- suicidal thoughts.

Discuss any feelings of low mood with your health care team.

Sometimes changes to behaviour may be a sign of changes to the way you think. Those close to you may be the first to notice and you can be screened to work out if there are likely changes to your thinking and how you process information. Your neurologist can advise if this is the case.

See *Further information* at the end of this section about our resources on emotions, and changes to thinking and behaviour.

“ Online programmes like mindfulness (cost-free) can be helpful, but you have to be willing to use such initiatives. Meeting people socially can help you remain positive and alternative therapies such as reflexology can be beneficial. Social media can play a part too.”

Intimacy and sexuality

For many of us, physical intimacy is very important. Touch and being close to those you care for shows affection and enables you to share emotional support. It can help to work out different ways to express how you feel.

“ I used to be able to indicate emotion, especially love and care for others, by use of my hands... when this means of communication is lost, misunderstandings happen, with loss of rapport.”

Intimacy with a partner does not have to include sex, but sex may be a significant part of your emotional life. You may worry about the impact of MND on sex.

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. Open discussion with your partner or potential partners can be very helpful. Some people find it difficult to ask questions about intimacy at health and social care appointments, but this can be useful. There may be simple answers to many concerns. We also provide candid information on sex and relationships.

See *Further information* at the end of the section about our booklet on *Sex and relationships*.

Rethinking and planning

With MND, things can change quickly. This means plans have to change too.

The urge to deny the diagnosis can be strong and often people ask ‘Why me?’ This is to be expected, but acceptance that life has changed can help you take control and adapt. Becoming informed about the disease will help you make decisions and find support when needed. This can help you achieve the best possible quality of life.

“ It really can’t be emphasised enough to listen to professionals who have helped people go through this before... Please listen, I know it is hard, but it could save you pain and keep you well that bit longer.”

Accepting change:

- means recognising and accepting what is, in comparison to what was
- means adapting to make life easier for yourself and your carers, for example, using assistive equipment
- does not mean giving up or giving in
- turns ‘Why me?’ into ‘What can I do?’

“ The easiest way to feel positive is to do something positive...ask an MND forum or Facebook group for ideas.”

Decision making:

- can include people involved in your care, but you have the final say
- can be reviewed as your symptoms change.

Staying in control:

- means trying to stay involved in the world around you, as MND can feel very isolating
- means giving yourself permission to laugh when needed, as humour can help ease difficult moments
- is about planning ahead to ensure support is already in place when needed
- means being aware of your future needs, while managing the disease one day at a time.

“ I have explained my symptoms in detail to those who help me. They have been better able to understand and respond to my needs.”

Emotional support and guidance

Ask your GP, and your health and social care team for guidance if needed. They can help you manage difficult emotions and medication may ease certain symptoms.

If you feel overwhelmed, ask your GP to be referred to a counsellor, psychologist or neuro psychologist for guidance. There can be long waiting lists for these services. However, specialist palliative or hospice care usually includes some counselling. If wanted, they offer practical and spiritual guidance too, for yourself and those close to you.

Complementary therapies may also be offered through palliative or hospice care, such as massage. These therapies may help relieve anxiety and certain symptoms. If you are not yet linked to a palliative care team, but wish to try complementary therapies, ask your GP how to seek registered practitioners in your area.

See Section 11: *Planning ahead for more information on palliative care.*

“ It helps put emotions in some sort of order by knowing support is there.”

Our helpline MND Connect provides information and emotional support. The team can also introduce you to our services and external services, as appropriate.

If you have access to one of our Association visitors in your area, they can support by telephone, email or through face to face visits.

Our local branches and groups offer a warm welcome if you would like to meet others affected by MND and share support. If this doesn't feel right yet, you can always attend a gathering at another time.

See Section 12: *How we can help you.*

“ It is comforting to be with people who understand, without explanations.”

Our online forum at **<https://forum.mndassociation.org>** also provides a safe place for you to share experiences, practical tips and support, with others affected by MND. You can read the forum posts without joining conversations if you prefer.

Key points

- Open conversations with those close to you can help you all understand each other's emotions and anxieties. This can help you find ways to manage how you feel and cope with challenges.
- Whatever emotions you experience, you are not alone and these feelings are usually a natural response to difficult circumstances. If overwhelmed, seek support from your health and social care team. You can also contact our MND Connect helpline (details provided next, in *Further information*).

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 6B:** *Complementary therapies*

From our guides and other publications:

Making the most of life with MND: a booklet about how to maintain interests and adapt.

Caring and MND: support for you: a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide: a booklet to help someone new to the caring role.

Changes to thinking and behaviour with MND: a booklet about support for these changes, if they happen.

Emotional and psychological support: a booklet about self-support and how to find professional support if needed.

Telling people about MND: our guide to help open conversations about the disease with family, children, friends, colleagues and professionals.

Sex and relationships: a booklet with guidance on ways to maintain intimacy.

Information to pass to your health or social care professionals:

Motor neurone disease: a guide for GPs and primary care teams

Cognitive change, frontotemporal dementia and MND

Caring for a person with MND – a guide for care workers

Supporting children and young people close to someone with MND

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at: **<https://forum.mndassociation.org>**

Samaritans:

A listening service for confidential support.

www.samaritans.org

Telephone: **116 123**

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

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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