4: Emotional impact

This section will help you to identify and manage some of the more difficult emotional responses you may feel after 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
4: Emotional impact

This section will help you to identify and manage some of the more difficult emotional responses you may feel after diagnosis.

Every individual is different and your emotions will be influenced by your own particular circumstances, culture and beliefs. Whatever responses you feel in the weeks and months following diagnosis, it is important to remember these reactions are natural and shared by many. You are not alone. There is help and support available.

Reactions

For most people, a diagnosis of MND comes as a shock. However, for some there can also be a sense of relief after a period of great uncertainty. Once you know what is happening, you can take action to make life as comfortable as possible.

Yet, as you begin to deal with the diagnosis and what it will mean, the range of emotional responses can feel very confusing. It is not uncommon to feel mixed emotions, as you can experience more than one distinct feeling at a time, such as anger and guilt.

You may experience:

- shock
- fear for the future
- disbelief at the diagnosis, and denial
- anxiety for family, children and friends
- grief for the loss of the future you expected
- anger at the medical profession or family and friends
- isolation because you suddenly feel different from others
- intense sadness
- guilt that you may be the cause of stress for others
- relief that you finally know what is happening to you.

Feeling overwhelmed

Some or all of these reactions may feel overwhelming for a while and you need to work through them at your own pace. You may need to get the situation straight in your own mind before seeking support or information. Gradually though, you may wish to review your life and plans.

One of the most difficult things at this time is to get a balance between keeping a positive mental attitude and accepting that you have a life-shortening illness. 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 think a lot about living and not about dying. I may not be around a year from now, but on the other hand neither might anyone else. Why spend time worrying about the worst scenario?”

Discussing and acknowledging feelings with those close to you is vital. MND affects them too and sharing highs and lows means you can all support each other. They may even wish to access information on the disease and support services before you feel ready to do so. They will have personal questions about what is happening and seeking information can help them to adjust.

See Section 5: Family, children and friends for help on how to handle these sensitive conversations.
If your partner or a family member helps to support you, we also provide information specifically for family carers. This includes emotional and practical guidance to help them cope, particularly as they face the challenges of the caring role.

See Further information at the end of the section for carer information.

Emotional lability

You may find you tend to laugh or cry at inappropriate times. This can be difficult to stop and you may feel out of control, which is often distressing for yourself, but also for those close to you, who may not understand.

This is called emotional lability (also known as pseudo-bulbar effect) and is a symptom of MND, though it is not necessarily experienced by everyone with the disease.

It is an abnormal motor response caused by the effects of MND on the pathway between the outer layer of the brain and the brain stem. This means your responses may not match how you feel. For example, you may laugh uncontrollably, but feel sad, or you may cry, but feel happy.

In many cases this is a temporary symptom that reduces over time, but if the responses are persistent and causing distress, talk to your GP. If your GP is not familiar with emotional lability, try to talk to an appropriate member of your health and social care team with experience of neurological conditions.

You may find that understanding the symptom is enough to help you and your family to manage the impact. Others find emotional lability limits where they go and what they do, and that medication or other assistance helps.

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

Depression

With any serious illness, it is quite normal to experience low moods at times.

If you find it particularly difficult to recover from feeling low, it may be time to seek some help. Try to be aware of signs such as:

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

Bear in mind that there could be other underlying causes for these effects which may be due to physical symptoms rather than depression. Whatever the cause, if they persist or feel overwhelming, you can seek help. There is no reason why you should have to go through them alone and there are effective treatments available. Speak to your health and social care team for guidance.

See Section 13: How health and social care professionals can help you.
Intimacy and sexuality

For many of us, physical intimacy is very important. Touch and being close to your partner can be an essential part of showing affection and sharing emotional support. Intimacy does not necessarily always include sex, but sex may be a significant part of your emotional life. Many people affected by MND worry about the impact of the disease on sexual expression.

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. However, open discussion with your partner can be very helpful. You may also find it useful to talk to someone from your health and social care team for guidance should you have specific questions.

You and your partner may have questions about how MND will affect intimacy and how you can solve these issues. We provide helpful and candid information if you have concerns.

See Further information at the end of the section for information sheets on sex and relationships.

Rethinking and planning

A diagnosis of MND may alter the direction you expected your life to take, but it should not stop you making new plans. By becoming as informed about the disease as you can, you can learn to manage it and find support. This will help you to 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."

The urge to deny the impact of the diagnosis can be strong, followed by ‘Why me?’ This is normal and understandable, but too much focus on this may delay how you take control of managing the illness. Although different for each individual, MND is always one step ahead. It is unpredictable and, for some, progression is rapid. It is important to become informed about the types of decision you are likely to face in the future.

The following may help you find a positive way to deal with the diagnosis:

Accommodating and accepting change:

• means adapting to change and being able to recognise what is now, in comparison to what was
• means using available support to make life easier, for example, using a walker or wheelchair for safer mobility when required
• does not mean giving up or giving in
• is proactive, turning ‘Why me?’ into ‘What can I do?’

Decision making:

• can be better supported through discussion with those close to you and your health and social care team, but ultimately, you have the final say
• should be flexible, as you may need to revise or reverse decisions as your symptoms change.

"It is easy for the person with MND to withdraw and for the carer to be preoccupied with caring. It is important to take time to remember to show the other that you still care. I can’t stress how important this is.”
Staying in control:
• means trying to keep involved in the world around you, as MND can feel very isolating
• means giving yourself permission to laugh when needed, as humour can help to defuse those difficult moments
• is about planning ahead to ensure support is already in place when you need it
• means being aware of your future needs, while managing the disease one day at a time.

“ It’s important to stress that although people may not want to discuss things immediately, they can always seek help at a later stage.”

Emotional support and guidance
For professional guidance please talk to your GP and your health and social care team. They can offer a range of assistance, from how to manage difficult emotions, to medication for specific symptoms.

If you are feeling particularly overwhelmed, ask your GP to be referred to a counsellor or psychologist for guidance, although there may be a waiting list. Palliative care teams and hospices usually offer counselling and spiritual guidance as part of the palliative care approach.

When you feel ready, you can read more about palliative care in Section 11: Planning ahead.

Some people affected by MND find complementary therapies help relieve stress and can be very calming. These should always be taken with a qualified and registered practitioner.

The MND Association is here to help you in any way we can, with advice, information and support. Our helpline MND Connect can direct you to services or just provide a listening ear. For many, joining a local branch or group of the MND Association to meet other people affected by the disease can be supportive. If you decide this is not for you, it may be something to consider at another time.

If you have access to an Association visitor in your area, they can support by telephone, email or through face to face visits.

See Section 14: How we can help you.

The MND Association online forum also provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can also view the forum conversations without joining if you prefer. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips.

See Further information at the end of this section for contact details.

“The MND Association is the cushion from the falling sensation you get when you are diagnosed.”
Key points

• Whatever emotions you experience, you are not alone and these feelings are usually a normal response to difficult circumstances. If overwhelmed, do seek support from your health and social care team.

• Talking to those close to you, and to your health and social care team, is an essential part of finding ways to manage how you feel and enable you to cope with the challenges ahead.

See Section 5: Family, children and friends for help on how to handle sensitive conversations with those close to you.

• If you feel persistently low and unable to manage, do seek help from your health and social care team.

Further information:

We have a range of numbered information sheets, including:

6A: Physiotherapy
6B: Complementary therapies
9C: Managing emotions
13A: Sex and relationships for people living with MND
13B: Sex and relationships for partners of people living with MND

We also provide the following publications:

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

Caring and MND: quick guide
a small A5 booklet to help someone new to the caring role become aware of available support.

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from MND Connect, our support and information helpline: Telephone: 0808 802 6262 Email: mndconnect@mndassociation.org. MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 14: How we can help you.

Online forum:
http://forum.mndassociation.org hosted by the MND Association for you to share information and experiences with other people affected by MND.

Samaritans:
Telephone: 116 123
The MND Association would like to thank the Tesco Charity Trust, and the Evan Cornish Foundation for their support which has made the production of Living with motor neurone disease possible.

The MND Association has been certified as a producer of reliable health and social care information. www.theinformationstandard.org

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

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