



2: Emotional and psychological support

This section looks at the emotional and psychological impact of thinking about end of life decisions.

The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

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

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

2: Emotional and psychological support

This section looks at the emotional and psychological impact of thinking about end of life decisions.



What should I prepare for emotionally?

Thinking about end of life is rarely an easy task. Some of the decisions you will face are likely to feel uncomfortable, yet everyone's experience will be different.

“ The basic truth is that anyone in my position or similar will have fears, but not all the fears will be the same...Everyone will be worried about something, so it's a case of trying to get that person to be comfortable, and to talk to them about their fears.”

Thoughts may persistently trouble you, such as:

‘What will happen?’

‘Will it be frightening for me and those who care about me?’

‘Will it hurt?’

‘Will I lose control?’

‘Will it be dignified?’

‘What impact will this have for my family and friends?’

All of these questions, and many more, may affect how you feel. Yet many people report that they feel relieved and much calmer having made their plans and knowing what is likely and less likely to happen.

“ I've been lucky. I had a very supportive team who I could discuss advance decisions with, but even this was hard emotionally. Now that I've done it I feel better.”

It is normal to expect heightened emotions when facing end of life decisions. It is a particularly sensitive time and every individual will have a different set of circumstances, needs and preferences. Your feelings will be personal to you, but influenced by those around you. You can experience more than one distinct feeling at a time, such as anger, guilt, sadness and a sense of relief.

You may experience some or all of the following:

- a sense of being overwhelmed, as end of life decisions can be complex
- fear for the future and what may happen to you
- anxiety for family, children and friends
- a sense of loss of control over your life and what will happen to you
- feelings of panic
- anger at the medical profession or family and friends, if they seem to be arranging things in a way that doesn't meet your wishes
- isolation, if you feel a sense of separation from others who are not in your position
- intense sadness for your own loss and for your family
- guilt that you may be the cause of stress for others

- tension with those close to you, as this may be stressful and tiring for all of you
- an intense closeness with those you love, as bonds can become tighter
- relief that you finally know what options are available to you and can express your wishes
- a feeling of resignation or acceptance.

These are all normal and expected reactions to challenging circumstances. With support from health and social care professionals, and those close to you, difficult feelings usually become more manageable over time.

Anticipatory grief

You, your partner, main carer, relations and friends will all be facing emotional upheaval during this time. There will be pressure to discuss sensitive issues that might feel upsetting. You may all experience what is known as 'anticipatory grief', where you begin to grieve for the loss to come and feel a sense of impending dread.

" You grieve on diagnosis. I was inconsolable for about a month, but then it got much better."

There will be grief for losses along the way too. The progressive nature of MND means that physical independence, expression, communication and activity may all be affected. This can sometimes be rapid. Not only are you likely to feel grief about dying, but about each limitation that MND may bring.

" He experienced increasing distress and frustration because of his symptoms, which were affecting his life and work significantly. It was distressing not only for him, but for all the family."

Talking openly to those around you can help to reduce some of the anxiety that anticipatory grief can cause.

See later headings in this section, *What can I do to help manage my emotions?* and *Who else can I talk to?*

This is important for everyone involved, as the grieving process can affect all those in your close circle. If you have a main carer who provides ongoing support, it can be intense for them, as they will be particularly aware of the disease progression. They will also find their relationship with you changing in order to meet the challenges of the caring role.

" Carers are just as important as the patient and their fears are for themselves as much as the person they are caring for. They need their own support."

See section 7, *Discussions with family and children*. Also *Further information* at the end of Part 1: *What do I need to think about?* where we provide details about our publications for family carers.

What can I do to help manage my emotions?

You will probably discover various ways to cope with emotional overload. If you find it difficult to show your feelings, try to allow yourself to express anger, irritation, tears – even laughter, as these can all help release tension.

It is okay to feel emotional about what is happening, but try to talk this through with those close to you and give them permission to do the same. You may even find this brings you closer. Without open communication, emotional tension can build and make it more difficult to tackle what lies ahead.

Often, it is the sense of losing independence and control to the disease that takes its toll. Many people with MND have said that taking positive action can help you feel more in command. This can help rebuild confidence, reduce frustration and lift you from sadness.

People living with MND have found the following helpful:

- doing something physical, like gardening, with assistive equipment to help you stay active for as long as possible
- planning a trip, event or holiday (many travel providers provide accommodation adapted for people with disabilities)
- seeking out experiences with family and friends that will provide lasting memories
- using speech and communication aids to help you maintain communication and social contact should your ability to speak and gesture be affected
- listening to music or going to music therapy sessions
- having physiotherapy, with a qualified physiotherapist who has experience of MND
- having hydrotherapy, where exercise is assisted and supported in water to help you move and flex joints safely
- trying one of the many complementary therapies with a qualified and registered practitioner (if wished, family members may be able to learn helpful massage techniques to provide help at home).

See Further information at the end of Part 1: *What do I need to think about? for a list of publications with details about therapies, equipment and ways to prolong your independence.*

“ The thing about MND is that the goal posts are constantly moving... But you just have to adapt as you change. It’s all about living life to the full.”

Local clubs for people with disabilities can help you stay active, for as long as you want to be involved. This can open up new opportunities, with a wide range of supported activities from sailing and riding, to swimming and music sessions. In most cases, support can be adjusted to meet your changing needs.

“ I’ve just finished doing an HND in fine art... I have an exhibition in May. It’s amazing and so cathartic. When I’m at the easel I’m not A. Smith with MND, I’m A. Smith the artist.”

You may also wish to seek out spiritual or religious support. Whether as part of a faith, a different type of belief or none, most people tend to ask ‘Why?’ when they are unwell and you may find it helpful to talk this through.

See later heading in this section, *Spiritual and religious support.*

There may come a time when you no longer feel that you want to travel far from home and activity becomes more limited. This can also have an emotional impact, as it may feel isolating. At this stage your immediate environment, communication ability, equipment, assistive devices and in-house entertainment become important to maintaining social links and the best possible quality of life.

This may need planning too. For example, assistive equipment can take time to arrange, deliver and install, so try to think ahead about your future needs. Always get an independent assessment of your needs first, before purchasing any equipment or assistive devices. This should be done through a relevant and qualified professional, such as an occupational therapist (OT). This can help you avoid costly mistakes. Some items may be available free through statutory services (through government or NHS funding).

How do I access professional help?

“ During this difficult and stressful time, it would have been helpful to have had a family counsellor... the challenge is to find support from someone who understands the issues being faced.”

If you are feeling particularly overwhelmed, ask your GP for guidance. You may be referred to a counsellor or psychologist, although there is often a waiting list. Your GP may be able to offer an alternative, such as referral to a support worker and many health and social care professionals can advise. Be aware that some counselling services may be free through the NHS or social services, but others may charge.

See also *Spiritual and religious support* later in this section.

If you have not been referred so far to a palliative care team or hospice, ask your GP if it can be considered. If you are planning ahead, this referral may provide access to wider services to guide you through end of life decisions and help you and those close to you manage the emotional impact.

Depending on your needs, this could include:

- counselling or psychological support
- spiritual or religious guidance
- access to complementary therapies
- family discussion of sensitive subjects, with professional support.

These services may not be offered automatically, so do ask your GP or palliative care team what is available and how to make the necessary appointments. If there is a waiting list for a service, don't let this deter you – should you reach crisis point at any stage, it is better to be progressing on a list than try to arrange support at short notice.

Who else can I talk to?

At times, you may need a listening ear outside of your immediate circle.

“ Sometimes I need to scream and there's no-one to scream to.”

Although health and social care professionals can help, they may only be available through appointment. So who can you contact if you need someone to talk to immediately?

The MND Association is here to help you in any way we can, through:

MND Connect: our helpline team can direct you to our services, external support or just provide a listening ear.

Association visitors: our voluntary visitors (where available), can provide support, guidance and information by telephone, email or through face to face visits.

Regional care development advisers (RCDAs): our regional professionals can support and guide when your needs are complex, and help to coordinate services on your behalf.

MND Association branches or groups: where informal support meetings are often arranged for people living with MND, or their carers. This enables you to share ideas and experiences with other people affected by the disease. If you decide this is not for you, it may be something to consider at another time.

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

See Section 15: *Help from the MND Association* for information about our care related services and contact details.

Spiritual and religious support

When approaching end of life, you may think about spirituality more, whether or not this is linked to faith. In short, you may be trying to make sense of life and death. This may include trying to resolve any conflict in your life or asking questions such as, 'Why me?', 'Who am I?' or 'What will happen after I die?'

Religious belief and spirituality can be expressed in a variety of ways and for many people this will include ceremony, rites and worship, particularly as part of a practising faith or religion. Others may explore spirituality outside of religion, through:

- cultural influences
- meditation and ritual
- deepening relationships and trying to understand how you relate with others
- interests of more than a functional nature, eg music, art, sport or a sense of the environment
- humanist or other beliefs
- therapies that aim towards general wellbeing.

If your identity has relied, at least in part, on what you have been able to do in life, you may find yourself seeking alternative meaning as your roles and purpose change with the progression of your illness.

You, and those close to you, may find it useful to:

- identify sources of strength you can draw on
- decide whether those sources will be helpful during this period in your life.

You may like to have support or guidance beyond your immediate family and friends. There is no guarantee that this will bring resolution, or heal psychological, emotional or spiritual pain, but it may give an opportunity to talk about your concerns at a detailed level and invite a wider view. For example, if you are linked to a hospice they can often provide counselling or more informal opportunities to talk.



“ The hospice appointed a ‘friend’ to us, whom my wife talks to a lot. It is really helpful for us and we keep in close contact... when you go there you feel like a friend not a patient.”

There are multiple avenues where you can find this type of guidance:

Specialist palliative care professionals: are skilled in communication and assessment of your needs relating to end of life support. All palliative care professionals are usually trained to be aware of the religious or spiritual needs of the individuals they support and should be able to direct you to appropriate guidance, but specialists may have a wider knowledge of external sources of help.

Hospice services: can offer listening, counselling and redirection to appropriate spiritual or religious guidance. If required, this is provided in conjunction with practical palliative and end of life care. Hospice services involve specialist palliative care professionals and volunteers.

Community faith leaders: can offer guidance and will be able to discuss questions about belief. Do not feel embarrassed if you no longer follow a faith, but would like to ask for their support. However, despite their natural association with births and deaths through ceremony, they may not be trained in end of life care or understand MND, so may not be equipped to answer practical concerns about the process of dying.

Representatives of other beliefs: can help you to consider spirituality without religion or faith. This may involve exploring your beliefs within a different framework such as Humanism. Again, they may not be trained in end of life care or understand MND, so may not be equipped to answer practical concerns about the process of dying.

Hospital chaplains: offer a multi-faith service with face-to-face visits to help you explore any spiritual concerns while in hospital. This listening and support service is open to multiple faiths or spirituality according to other beliefs.

Social workers: are trained to consider cultural needs, faith and other beliefs. They can advise you about how to find specific help and guidance.

Specialist organisations: can be useful sources of information and support. Depending on their aims, they may provide a platform for debate, a helpline, directions to other services, guidance or resources. Ask your health and social care professionals for suggestions. These organisations may be linked to a religion, belief or general end of life concerns, such as The National Council for Palliative Care (NCPC) or Dying Matters.

See Section 16: Useful organisations for contact details and descriptions of these organisations.

When the time comes, you may have religious or spiritual requirements you want observed during or following your death. You may not want to leave it all to your family or those close to you to sort out. These requirements may be very important to you and you may worry about how they will be met. Talking to funeral directors will help you find out what is possible regarding any service or ceremony held after your death, and how your needs can be best met. You may need specialist services to observe particular cultural rites.

See Section 10: What happens after I die?

Spiritual or religious concerns can also impact on your decisions about medical care and future withdrawal of treatment. You can ask specialist palliative care professionals to help you think about this in connection to your beliefs. This will help you to understand what will happen and what will not happen if you make a decision. You may then wish to consult with a faith leader to determine a course that feels right for you.

See Section 9: Advance care planning and advance decisions.

If you would like further assistance on where to go for spiritual or religious support, the MND Association can help to direct you to appropriate sources through our helpline, MND Connect, and other services.

See earlier heading in this section, Who else can I talk to? for contact details.

Changes to behaviour and emotion

Some people with MND show behavioural changes, such as restlessness, lack of drive, acting impulsively, eating lots of sweet foods, fixating on one activity or routine, or lacking empathy for others. If you have noticed any changes, there can be a variety of causes:

- the emotional impact of the diagnosis
- breathing and respiratory problems, which can make it difficult to sleep well and cause fatigue
- general tiredness from the extra effort required if movement and mobility have been affected
- frustration and anger, as symptoms and disability increase
- infections, such as chest or urinary infections, which can lead to confusion
- a symptom called emotional lability, which affects some people with MND, where you tend to laugh or cry at inappropriate times
- changes to thinking and behaviour (called cognitive change), which affect some people with MND.

See Section 4: What to expect as the disease progresses under the heading Changes to thinking and reasoning.

See section 9: Advance care planning and advance decisions under the heading Do I need anyone to act on my behalf?

What is emotional lability?

Emotional lability is a symptom of MND (sometimes called pseudobulbar affect), but does not affect everyone with the disease. It can set off unexpected emotional reactions, caused by the effects of MND between the outer layer of the brain and the brain stem.

If this happens to you, it can leave you feeling out of control. It can also be distressing for those close to you, who may not understand. Your responses may not match how you feel. For example, you may laugh uncontrollably when you are feeling sad, or you may cry when you are feeling happy.

If you have this symptom when trying to deal with end of life decision making, it may place additional pressure on conversations that already feel difficult.

Will this keep happening?

In many cases this is a temporary symptom that reduces over time. If the responses are persistent and cause distress, discuss this with your GP. If your GP is not familiar with emotional lability, ask for guidance from a health and social care professional 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 it limits where they go and what they do, but medication or other assistance can help.

It is more common to experience emotional lability if your ability to think and reason have been affected. However, emotional lability does not necessarily mean that changes to thinking and reasoning will happen.

Sexual expression and intimacy

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.

If your partner is also your main carer, and they provide your personal care, this can also impact on the intimacy of your relationship.

Where end of life decisions are concerned, this can become a greater issue. For example, treatments may involve clinical equipment, such as breathing machines, feeding tubes or profiling beds (beds that can be adapted for positioning). This can impact on confidence, body image and self esteem, and create worry about the equipment itself.

However, open discussion with your partner can be very helpful and your health and social care team can provide guidance.



“ There was a time when we had to have two single beds, having shared a bed for twenty years... every night he adjusted his bed so that it was exactly the same height as mine. It was so important to me that we had that time together – being able to reach across and touch him.”

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 Part 1: What do I need to think about?* for a list of additional publications.

Key points

- Even if it feels hard to talk about end of life, do try to have these conversations early. If MND affects your speech and communication, discussion may become more difficult.
- You cannot change the diagnosis or prevent what will happen, but you can help to ensure your wishes are respected. Confronting end of life is the most positive action you can take, so that when the time comes, you can die with dignity and with as little fear as possible.
- If you do feel overwhelmed, find someone to discuss this with. It can be a family member, a friend, a health or social care professional, someone at the MND Association, or members at a branch or group meeting. You can also join our online forum to share experiences with a wider community affected by the disease.

See Section 15: *Help from the MND Association* for information about our care related services and contact details.

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