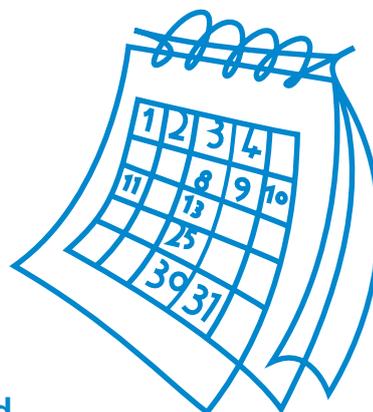




# 1: Why plan ahead?

This section explains why it is beneficial to plan ahead for end of life.



**“ Coping after such a devastating diagnosis is always a challenge – but help is available. With the right care and support, many people have told us they can maintain their quality of life and find ways to manage day-to-day tasks. Even the later stages of what is ultimately a life-shortening disease can be met with dignity and a sense of control, when the right support is there.”** Sally Light, CEO at the MND Association

By choosing to read this guide, you have decided to explore what end of life may mean for you. By researching your options, you begin to take control of how your end of life decisions can be managed.

Most people tend to avoid talking about end of life. This is natural, as our instinct to survive is strong and we focus on living and looking forward.

**“ I didn’t think about end of life before I had MND. You just don’t.”**

When your future is threatened, it can leave you feeling devastated. Your dreams and goals are suddenly in question and your routines and plans have to be reassessed. A period of shock usually follows diagnosis, which extends to family and friends too. You may even feel a sense of denial when told you have a life-shortening disease. This can seem unreal or you may hope that the diagnosis is wrong.

**“ We all have to face fear of death at certain points in our life and serious illness brings this to the fore. From our experience, it is better to be in a position where you feel as prepared as you can be.”**

Fear of death is often linked to 'not knowing' what is ahead. This can be made worse by reports you may hear, which are not always based on fact. You may find your fears easier to deal with by finding out about end of life care and the options available. This guide will help you start gathering information.

## How will planning ahead help me?

Planning ahead makes it more likely that you will receive the care you want, rather than relying on services being available at short notice. Most people find that making plans can be reassuring, enabling choice and control over what happens in the future, as far as is possible.

It’s important to remember that:

- thinking about end of life does not bring it closer
- you have the right to change your mind and change your plans at any time
- once you have made your plans you can get on with living
- many people find that planning ahead brings peace of mind.

Let your loved ones know about the decisions you make and have regular discussions, as your views may change. It can be a huge relief for those close to you to be made aware of your choices, so they can try to respect your wishes.

**“ Once you’ve done it, you can put it away in a cupboard. You can relax...and you feel better for doing it.”**

If your speech and communication are affected, try to have difficult conversations as early as possible, so you can discuss sensitive and complex issues more easily. If you feel tired or emotional doing this, you can tackle it in stages.

**“ My approach is to be open and frank and then move on. The problem is that, as a society, there is a huge taboo about dying.”**

Whatever decisions you make, it is important to recognise that the health and social care team, including local palliative care services, can support you and your family, and help to ease your symptoms and worries.

**See later heading in this section, *Are end of life care and palliative care the same?***

## **What type of plans should I be making?**

Planning ahead is about being prepared. Doing this as early as possible means you have support and equipment in place when needed. If not, you may find it challenging to get things arranged as your needs become more urgent. Planning usually includes:

- getting your financial and legal affairs in order, such as writing a will and ensuring those close to you are aware of important records
- asking your health and social care team about treatment options, so that you can make decisions about these at the right time

- considering future housing or nursing care options in case your care needs become complex
- caring for children and planning for their future
- ensuring your preferences about your care are written down, in case you become unable to express them in the future
- having open discussions with your family carers, relatives and friends so that everyone is aware of your choices
- identifying who would make decisions on your behalf should you become unable to do so yourself
- deciding on your preferred place of care and death, such as at home, or in a hospital or hospice
- being prepared for emergencies
- deciding on funeral arrangements, if you have wishes you would like to be respected.

**See Section 7: *Discussions with family and children* and Section 8: *Putting affairs in order.***

You may want to explore your spiritual or religious beliefs or have practical questions about dying: ‘What is likely to happen to me?’ and ‘How will I die?’ are frequently asked questions.

**See Section 2: *Emotional and psychological support* and Section 5: *How will I die?***

Not everyone will necessarily agree with your choices, which can feel challenging. Open discussion can help understanding and a member of your health and social care team may be willing to guide these conversations.

**“ We’re born and we’re all going to die. Dying is as important as being born.”**

## When is it best to start discussions about end of life?

Discussions about end of life can feel overwhelming. Some prefer not to think about this at all, while others prepare for the later stages of MND as soon as they can.

**“ I was in denial at the beginning, but as soon as you can come to terms with it, you can have a better quality of life for the rest of your life ...Now everything is an opportunity to live life.”**

Because the progression of MND is unpredictable and sometimes rapid, your health and social care team may introduce end of life discussions before you feel ready.

If you are asked to think about end of life shortly after diagnosis, you may worry that you are already in the later stages of MND. However, there are good reasons why early discussion may be encouraged, as:

- speech and communication can be affected by MND, making it tiring and more difficult to have detailed discussions as the disease progresses
- cognitive impairment (changes to thinking and reasoning) can also occur for some people with MND
- you may want to consider who you would like to act on your behalf, should you become unable to communicate or make decisions.

**See Section 9: *Advance care planning and advance decisions.***

Opening the conversation is the first step, but you don't have to plan everything at once. Some decisions, such as options for treatment, may only be necessary if you begin to get certain symptoms. However, finding out about these as early as you can, means you are prepared to make timely choices, if needed.

**“ Issues don't always come out in the first conversation. This needs time to evolve and for relationships to build. People need time to think things over.”**

## What if I have a slower progressing type of MND?

If your MND symptoms are progressing slowly, you may feel you can wait longer before making end of life decisions. Your circumstances and outlook might change and there may be less urgency.

**“ We haven't yet had that conversation, as he's still quite good. The time comes when it's right, and it's obvious that the conversation will need to happen.”**

However, as symptoms become more apparent, diagnosis may change from a slower to a more rapid form of MND. This means there is still a benefit in considering your plans.

Ask your neurological consultant if you are unsure about the speed of your progression and which type of MND you have, although this is not always easy to determine.

## How do I plan ahead?

Gather as much information as you can from your health and social care team. Although having these conversations early is valuable, try not to rush major decisions. You may find your views adjust as you find out more detail.

Once you know what can be done and have thought about what you would prefer, you can tell others about your wishes and leave written instructions to help guide them.

**“ Family and friends don't necessarily understand or have a full picture of all the issues.”**

The more informed you are, the easier it will be to explain to others how you would like your future care to happen.

**“ I wanted to know everything.”**

You can plan ahead by:

- making decisions about future treatments, such as tube feeding or help with your breathing
- determining the best timing to introduce treatments, with further help from your health and social care professionals
- creating an advance care plan in which you leave written instructions about your medical and social care
- clearly recording any Advance Decisions to Refuse Treatment (ADRT) that are important to you
- thinking about contingency planning to ensure you, your main carer and your family know what to do in unexpected situations
- investigating how to get help with care at short notice, should your main carer be unable to support you at any time

- nominating someone you trust to make healthcare or financial decisions on your behalf, through a Lasting Power of Attorney (LPA) in England or Wales. Enduring Power of Attorney (EPA) provides a similar function in Northern Ireland
- ensuring those close to you know what your wishes are and where any related documents or forms are kept.

**See the following sections for more detail:**

**4: What to expect as the disease progresses.**

**6: What care is available?**

**9: Advance care planning and advance decisions.**

In most cases, you can change your instructions at any time, but be careful when making financial decisions, which you may not be able to reverse. As appropriate, ask a solicitor, trusted financial adviser or benefits adviser for guidance.

## Are end of life care and palliative care the same?

When making decisions about end of life, you will often hear the terms palliative care or end of life care. These terms are used throughout this guide to mean the following.

### **Palliative care:**

Palliative care is additional support for people with a life-shortening illness. This may be provided from diagnosis onwards.

With MND, palliative care may be provided through your primary care team (your GP and community nurses), a neurological clinic, your MND care centre or network, or specialist palliative care services (in your home, a hospital, hospice or day centre).

These services work together to help you achieve the best possible quality of life, including symptom control and support for psychological, social, spiritual, religious or other needs. This extends to your immediate family and carers.

**See section 6: What care is available?**

## End of life care:

End of life care concentrates on identifying your needs, and those of your family and carers, during the last phase of life and into bereavement. This usually means the final 12 months and includes palliative services. The primary focus is to support the needs, preferences and wishes of the person approaching death, to help them live as well as possible until they die, and to die with dignity.

## Key points

- Discussing end of life does not bring it closer, but at some point you will probably want to make decisions about your future care. If this is planned and communicated, there is more likelihood that your wishes will be understood and respected.
- The progression of MND can be rapid, but having conversations about your wishes helps you to plan ahead and give your loved ones personal goodbyes.
- It can be a relief for those close to you to have your wishes about your future care written down. If you become unable to communicate for any reason, it can help them to feel more confident and take away the responsibility of having to make those choices for you.
- It is better to plan ahead, rather than leave everything to chance. If you are in any doubt about a choice you have made, even in a legal document, this can be amended.
- Even if you feel unsure about what you may want, it is still useful to discuss and write down general preferences about your future care. This may not be specific, but it can still help to guide others involved in your care if decisions need to be made on your behalf.

## Impact from the coronavirus pandemic

We hope the coronavirus pandemic ends soon. Until that time, you may also need to consider the impact of this in any decision-making or planning. For guidance see our web hub at: [www.mndassociation.org/coronavirus](http://www.mndassociation.org/coronavirus)

“ Don't assume something can be provided in a timely way, especially where services have been impacted by the Covid pandemic. This is tough, but you'll only know how long something will take by asking. The sooner you ask, the better.”



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For references and acknowledgements please  
refer to the full guide, *End of life: A guide for  
people with motor neurone disease*.

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

Telephone: **0808 802 6262**

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



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