



## 5: How will I die?

**This section provides information about dying and how this might be managed with MND.**

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](http://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](mailto:mndconnect@mndassociation.org)



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

## 5: How will I die?

This section provides information about dying and how this can be managed with MND.



Please be aware that the following pages contain sensitive information. Read this information when you feel ready to do so. You can always return to this section later.

“ I know I’m going to die with this...I’m not afraid of dying, but I am afraid of how I’m going to die. Whenever I’ve broached the subject I’ve been told, ‘Don’t you worry about that. We’ll make sure you’re comfortable.’ But that doesn’t deal with the fears.”

You may worry about distressing symptoms towards the end of life, such as choking. Mild or severe choking can be stressful for you and your carer at the time, but it is extremely rare for this to be a direct cause of death. In reality, most people with MND have a peaceful death.

**See Further information at the end of Part 2: What is likely to happen? for a list of publications to help with symptom control, including Information sheet 7A - Swallowing difficulties, which contains detailed advice on how to manage choking.**

The final stages of MND will usually involve gradual weakening of the breathing muscles and increasing sleepiness. This is usually the cause of death, either because of an infection or because the muscles stop working.

Specialist palliative care supports quality of life through symptom control, practical help, medication to ease symptoms and emotional support for you and your family.

“ I asked ‘How is he going to die?’ and the palliative care consultant said, ‘I think he’s going to have a respiratory arrest.’ Afterwards I said, ‘I’m not sure I wanted to know the answer to that question, but thank you for answering it.’ The consultant said that he had found that conversation difficult too. It was nice that he acknowledged this. It was just two human beings struggling with the same thing.”

When breathing becomes weaker, you may feel breathless and this can be distressing. However, your health care professionals can provide support to reduce anxiety.

You can also receive medication to ease symptoms throughout the course of the disease, not just in the later stages. If you have any concerns about the way medication will affect you, ask the professionals who are supporting you for guidance.

Try to keep discussion open with your health professionals. If this becomes difficult, your carer or family can ask what is happening, so they know what to expect. Medication to manage symptoms in later stages may make you feel sleepy and not fully aware of people and events. It helps if your family are prepared for this. In many cases, medication can be adjusted to find a level that works best for you.

**“ I am a retired nurse and had conversations with my husband about medication for anxiety if his breathing became shallow. In the end this is what happened and he died peacefully in the hospice. Medication was given at his request and he was in control.”**

Further weakening of the muscles involved in breathing will cause tiredness and increasing sleepiness. Over a period of time, which can be hours, days or weeks, your breathing is likely to become shallower. This usually leads to reduced consciousness, so that death comes peacefully as breathing slowly reduces and eventually stops.

Sometimes the breathing pattern can change just before death, with previously deeper breaths becoming much shallower.

For people using ventilation, the palliative care team will be able to offer advice about when it might be best to discontinue its use.

## Share your worries

**“ I know what the end is likely to be and I’ve put that away in a mental box and locked it away. Otherwise I wouldn’t be able to enjoy the rest of my life.”**

For many people, death is a difficult subject to discuss or think about. We hope this has helped you to understand what might happen in the final stages, but we also know that some people may feel overwhelmed by grief and sadness as they think about the end of their life.

You may find it helps you, your carer and family to share concerns or worries - ask your GP, specialist palliative care professionals or another professional for support when needed.

If you have an MND Association visitor, they will be able to listen and offer guidance. You can also contact our helpline, MND Connect, if you have any questions or need emotional support.

**See Further information at the end of Part 2: What is likely to happen? for our helpline contact details.**

## Key points

- Discussing dying may seem frightening, but the unknown can create more fear. If it helps, ask your specialist palliative care professionals or neurologist for guidance.
- In the majority of cases, death with MND is peaceful and dignified.
- Making an Advance Care Plan or Advance Decision to Refuse Treatment, can help those around you understand your wishes if you become unable to communicate. This includes instructions on your preferred place of death, as this may need specific arrangements.

**See Section 9: Advance care planning and advance decisions. Also see Section 4: What to expect as the disease progresses for details about our MND Just in Case Kit to help with breathlessness, anxiety and choking.**

## Impact from the coronavirus pandemic

Visiting people in hospital, hospices and care homes has been restricted during the pandemic, particularly where there are instances of Covid-19. Telephone or online communication may help, depending on symptoms. In some cases, limited visiting can be arranged under set rules. Ask those providing the care for guidance and find our coronavirus information at:  
**[www.mndassociation.org/coronavirus](http://www.mndassociation.org/coronavirus)**

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For references and acknowledgements please  
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This resource has been evidenced,  
user tested and reviewed by experts.