



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

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

5: How will I die?

This section provides information about dying and how this might 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 do not die from a frightening event, but 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 services focus on quality of life and symptom control. This includes practical help, medication to ease your symptoms and 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 and social care professionals, such as your GP, community nurse or members of the specialist palliative care team can support you to reduce anxiety.

You can also receive medication to help reduce symptoms as they become more severe, not just in the last stages of life. 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.

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.

Talk it through

“ 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 and your carer and family may find it very helpful to talk through any concerns. You may also wish to discuss your worries and fears with your GP, your specialist palliative care professionals or another health and social care professional who can continue to offer support and advice throughout end of life.

If you have an MND Association visitor, they will be able to listen and offer you reassurance. 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

- While the thought of discussing the process of dying may seem frightening, not knowing what may be ahead may create more fear. If you are still concerned and would like more detail, ask your specialist palliative care professionals or neurological consultant for additional guidance about the final stages.
- It can be reassuring to know what type of support is available at the end of life. Symptoms can be well managed and, in the majority of cases, death is peaceful and dignified.
- Any statement you write down about your end of life care, whether by Advance Care Plan or Advance Decision to Refuse Treatment, will help those around you to understand your wishes should you become unable to communicate.
- If you have a preference about where you want to die, ensure you discuss this with your family and specialist palliative care professionals. It may not always be possible to meet your choice, but try to ensure this has been recorded in an Advance Care Plan or an End of Life Plan. There may be certain arrangements that need to be made to enable your preference. Having this written down will be helpful.

See Section 9: Advance care planning and advance decisions.

See the heading *Breathing* in Section 4: What to expect as the disease progresses for details about our MND Just in Case Kit. This box can be ordered by your GP so that you can keep medications at home to ease breathlessness, anxiety and choking.

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

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