MND Association

8C
Withdrawal of ventilation with Motor Neurone Disease

Information for people with or affected by Motor Neurone Disease (MND)

With MND, the muscles that help you breathe can weaken and you may be using assisted ventilation support. You have the right to stop using this breathing support if you choose. This information sheet explores the process of withdrawing ventilation to help you make informed decisions. You may also have breathing problems with Kennedy’s disease, but these are usually less severe. This content includes:

Trusted Information Creator
Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk

This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in Section 6: **How do I find out more?**

1. Why do I need to think about withdrawal of ventilation?

This section contains sensitive details about end-of-life decisions. Read this when you feel ready. This guidance may help you make informed choices.

Mechanical help with breathing is called ventilation. The two main types are:

- Non-invasive ventilation (NIV) is provided by a machine to help you breathe normal air through a mask.
- Invasive ventilation (tracheostomy) is provided by a machine to help you breathe normal air through a tube nto your windpipe, through the front of your neck.

Ventilation can ease symptoms such as tiredness, poor sleep and morning headaches, and may help you live longer. However, it cannot stop symptoms from progressing and your breathing will continue to weaken.

For more about breathing support, see information sheets:
- **8A Support for breathing problems**
- **8B Ventilation for motor neurone disease**.

Do I have a choice?

Yes. If you choose to use ventilation, you can continue for as long as you wish. You can also decide to stop at any time (known as withdrawal), even as your breathing gets worse. The choice is yours.

As breathing muscles weaken, you may become more dependent on your ventilator. If you are fully reliant, it means you will no longer be able to breathe effectively without help of the machine. This means your life is at risk if you stop using it. Withdrawal in these circumstances usually leads to a natural death in a short time.

“I think it’s important for me to understand, broadly speaking, what will happen and what the main decisions, options and changes will be.”

You can withdraw a life-sustaining treatment such as ventilation, even though it is likely to result in death. If you feel a treatment is no longer helpful, or has become a burden, you can ask for it to be stopped. This is your legal right.

Withdrawal of life-sustaining treatment is not the same as assisted dying. Assisted dying means deliberately taking action to hasten or speed up the process of death, which is illegal in the UK. By contrast, withdrawal means allowing the natural course of your illness to happen.

Why it helps to plan ahead

Some professionals may not be experienced with ventilation withdrawal in MND and may feel uncertain about the law. In some cases, a professional might even refuse to be involved if they worry it could be mistaken for assisted dying. If this happens, ask to be referred to a specialist palliative care team.

Having early conversations about your wishes can ensure:

- you get the support you need in the way you want
- plans can be made in good time, to avoid rushing decisions at a later stage
- your wishes are known and can be respected, even if you later cannot speak or make decisions (for example, through written instructions.)

It helps professionals to know that you have made an informed decision and that you are settled on your choice. They can also find these decisions challenging. They have a duty to make sure you understand what is likely to happen if you continue to use ventilation and the consequences of stopping it. Whatever you decide, you can change your mind at any time.

“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.”

For more about planning future care, see section 3:
How is withdrawal of ventilation arranged?

2. Who needs to be involved in discussions?

When thinking about your future care, it helps to share your wishes with the people most involved. This includes possible decisions about stopping treatments such as ventilation. Your family, carers and healthcare professionals all need to know what you would like to happen, and in what circumstances.

Why do early conversations matter?

It can be tempting to delay sensitive conversations, but complex discussions may become harder over time because of:

- extreme tiredness (fatigue)
- changes to speech and communication
- changes in thinking or processing information (up to half of people with MND may experience this, though the impact is usually mild).

Having discussions sooner helps everyone understand your wishes and avoids misunderstandings later.

> **“Although we were a close family, we didn’t talk much about what was happening or what might happen in the future. I wish we had talked more because a lot of my worries would have been dealt with.”**

How can I help those close to me?

Family members and carers may have their own hopes, fears or beliefs, which may be different to your own. These conversations can be emotional, but open discussion usually helps everyone.

If needed, ask your health or social care professionals to help guide the discussion. They can explain your options clearly in full and help answer any questions or concerns.

Professionals may also find these discussions challenging. Relevant experts such as palliative care and respiratory specialists can provide appropriate support. You can be referred to specialists by an MND co-ordinator at an MND care centre or network, or a specialist nurse at a neurological clinic.

> **“Everyone will be worried about something, so it’s a case of trying to get that person to be comfortable and talk to them about their fears.”**

What questions can I ask at appointments?

Being fully informed helps you make choices that feel right for you.

Planning the withdrawal

- How are my breathing symptoms and other MND symptoms likely to progress?
- How will the progression of my symptoms affect my future care?
- How will I know if I have become reliant on ventilation?
- Which named professionals will help me with the withdrawal process, and how can I know if they have the appropriate experience?
- Where can withdrawal happen and can I choose who will be there, including which professionals, family members or spiritual leaders?
- Who will support my loved ones if there is a risk to my life?
- Who can help me discuss other end-of-life decisions and choices?

Managing the withdrawal

- If I choose to stop ventilation, how will my symptoms and anxiety be managed, especially if I have become reliant?
- What exactly will happen and how long might it take?
- Will I feel pain, gasping, or choking?
- If I change my mind during or after withdrawal, can ventilation be restarted?
- Will I still be aware and able to communicate any change of mind or my wishes (with support from communication aids if needed?)

"It's not pleasant having to think about and face these things, but it's necessary."

3. How is withdrawal of ventilation arranged?

Professionals may not raise sensitive issues unless they think you are ready, so let them know if you are. If thinking about stopping ventilation, the first step is to discuss this with your GP, healthcare specialists, family and carers. Often, these conversations lead to wider questions about planning for end-of-life.

"If you or your carer have a faith, it may help to discuss your wishes with a spiritual or religious leader alongside your healthcare team."

How does mental capacity assessment work?

Because withdrawal of ventilation carries a risk to life once you are reliant, your mental capacity will be assessed before a decision can be made.

Mental capacity means your ability to make decisions for yourself. In England, Wales and Northern Ireland this is guided by the Mental Capacity Act 2005, which is based on five key principles:

1. You are assumed to have capacity unless proven otherwise
2. You must be given all practical help to make a decision before being treated as unable to do so
3. You are not treated as lacking capacity just because you make an unwise decision
4. If you do lack capacity, anything done for you must be in your best interests
5. Any decision made for you must be the least restrictive of your basic rights and freedoms.

See the Act online at: **www.legislation.gov.uk/ukpga/2005/9**

In Scotland, this is guided by the Adults with Incapacity (Scotland) Act 2000.
You can read the key principles at:

www.gov.scot/publications/adults-with-incapacity-act-principles
and the full Act at: **www.legislation.gov.uk/asp/2000/4/contents**

Once your wishes are clear, withdrawal can be planned either in the near future or later on. As your illness progresses, your health and social care team will revisit your decisions with you to make sure they still reflect your wishes.

What are advance decisions?

If you are worried about becoming unable to communicate or make decisions for any reason, you can record your wishes in advance.

An advance statement lets you note your preferences, such as withdrawal of ventilation. This is not legally binding, but it helps guide professionals if you cannot speak for yourself. However, some professionals may find it difficult to agree to withdrawal of ventilation from an advance statement, due to risk to life.

An Advance Decision to Refuse Treatment (ADRT) is legally binding if completed correctly, and your wishes must be followed. It allows you to refuse or withdraw specific treatments in certain circumstances.

For example, you can state that you do not want ventilation started, or that you wish for it to be withdrawn if you become fully dependent and no longer able to communicate.

To be valid, an ADRT must:

- clearly state which treatments you are refusing and in what situations
- show that you understand this could put your life at risk
- be signed and witnessed.

Keep the original in a safe but accessible place (not locked away) and give copies to all those involved in your care, so they are aware of your wishes. Update it regularly, as doubts may arise if your situation or views appear to have changed.

You can also use an ADRT to make sure that new treatments are not started if you do not want them. This is what is meant by a refusal of treatment.

For example, in an emergency you may be given invasive ventilation (tracheostomy) without being asked first. If you do not want invasive ventilation or other treatments to be introduced, even in an emergency, make sure this is clearly written in your ADRT.

Are there options for someone to help me with decisions if needed?

Every effort should be made to support you to communicate your own wishes, including using communication aids. However, you may decide to give someone you trust responsibility to act on your behalf, in case you become unable to communicate or make decisions.

> **“I felt it was important to plan ahead now, as I can always change any wording if I want to. I wanted something in place in case I deteriorate and, because I have speech problems, I didn’t want any misunderstandings.”**

Lasting Power of Attorney (LPA) (England and Wales)

An LPA lets you appoint someone you trust to make decisions for you if you become unable to do so. This can cover either healthcare or financial matters, or both.

Enduring Power of Attorney (EPA) (Northern Ireland)

An EPA lets you appoint someone you trust to make decisions for you if you become unable to do so. This can only cover financial matters.

Continuing and Welfare Power of Attorney (Scotland)

This enables someone, or more than one person, to look after your financial affairs and health and welfare decisions.

Each option for power of attorney is a registered legal document, which means a fee will be charged at the time of submission. You may be entitled to a reduced or waived fee under certain conditions or if you are receiving specific benefits. Check first before submitting the document.

For more guidance on power of attorney, ADRT and recording your advance guidance, see information sheet: **14A Advance Decision to Refuse Treatment (ADRT) and advance care planning**. For wider guidance about planning ahead, see our guide: **End of Life care**

4. What happens when ventilation is withdrawn?

If you are not fully reliant on ventilation, you may still be able to breathe on your own when your mask or tube is removed. However, your breathing is likely to be weaker than before you started ventilation, as your symptoms will progress.

When you stop using it, you will be supported with medication and care to reduce any difficulties, such as breathlessness or anxiety. Medication is usually started before ventilation is stopped.

If you are fully reliant on ventilation, a natural death is likely to follow the withdrawal. The time this takes is difficult to predict. It could be as quick as 15 minutes, a few hours, or occasionally a day or more.

During this time, you will be closely supported to make sure any symptoms are managed, and you remain comfortable.

See section 2: **Who needs to be involved in discussions?** for suggested questions that may help reduce fears and worries.

> **“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.”**

Which professionals will be involved?

At least two professionals, preferably with experience of ventilation withdrawal, should be present to support and guide you through the process. Ideally, these should include:

- a palliative care specialist (doctor or nurse)
- a respiratory or ventilation specialist.

Other professionals, such as your GP and care workers, should also be informed so that they can support you and your family before, during and after the withdrawal.

> **"Having someone to guide you through, at the right time for you, is so important."**

What steps are taken with the withdrawal process?

Withdrawal of ventilation is carefully planned and usually involves:

- information sharing and discussion with everyone involved
- preparation and planning, including making sure the right professionals are present
- medication to manage symptoms, before and during withdrawal
- ensuring that symptoms are well controlled before fully stopping ventilation
- withdrawal of ventilation, with ongoing medication and reassurance to minimise any distress
- support for family and friends, if present, during and after the process.

It may take a week or two following your decision to withdraw treatment to make the necessary arrangements especially if the withdrawal is to take place at home. This time is essential to ensure that the correct professionals, equipment and medications are in place to support your withdrawal and ensure your comfort.

If you want certain family members or friends with you, they may also need time to travel.

If you have a preference about your place of death following withdrawal, discuss this with your family and specialist palliative care team. Your wishes can often be met but may need planning and arrangements to enable your preference. Recording them in an Advance Care Plan or End of Life Plan makes it easier for professionals to follow.

Family members or friends are not expected to take part directly in the withdrawal of ventilation, unless they specifically ask to. If they do, this should be discussed in advance so professionals can support them and consider the emotional impact.

After the withdrawal, family and friends present are encouraged to seek follow-up support from professionals to help manage any emotions.

How will I die if a natural death happens after withdrawal?

Knowing what to expect can help reduce fear. Facts can often feel less worrying than the unknown.

If you rely on ventilation, a natural death is likely to happen shortly after withdrawal, due to the weakening of the breathing muscles. This weakness is usually the cause of death with MND or Kennedy's disease whether you use ventilation or not.

The following may help to explain how this happens. The process is often gentle and peaceful. During the final stages:

- breathing becomes gradually weaker and more shallow, which could be over hours, days or weeks.
- you usually become increasingly sleepy and lose consciousness
- breathing slowly reduces and eventually stops.

For more about the later stages with MND, see our guide:
End of Life care.

Sometimes lips or hands turn slightly blue as oxygen levels fall. This usually happens when the person is already unconscious, but it can be worrying and upsetting for family to see, so it may be useful for them to know that this might happen.

> **"It is better to be in a position where you feel as prepared as you can be."**

Breathing patterns may also change just before death, with previously deeper breaths becoming much more shallow. These changes are natural and not usually distressing for the person.

Medication is used to relieve any breathlessness or anxiety and is started before withdrawal to avoid distress. These medicines can make you feel drowsy, and you may not be fully aware of people and events happening around you.

If you prefer to stay more awake, doses can often be adjusted to balance comfort with awareness.

5. What other support can be provided?

For many people, conversations about death and dying can feel very emotional. Thinking about the withdrawal of ventilation may bring these feelings into focus.

We hope this information sheet has helped you understand what might happen during withdrawal and to prepare for decision making.

We also recognise that you and those close to you may still feel overwhelmed when thinking about end-of-life. Sharing your concerns can make a real difference.

Your GP, specialist palliative care professionals, and other members of your health and social care team can all offer information, reassurance and support.

See our booklet: **Emotional and psychological support**.

Can anyone help me and my loved ones with fears and emotions about dying?

Knowing what to expect often makes conversations about dying feel less frightening. If you or your family are still concerned and want more detail, you can ask your specialist palliative care professionals or neurological consultant for additional guidance about the final stages.

Some people find comfort in talking with a counsellor, faith leader or peer support group. These options can provide space to explore fears and feelings outside of the clinical setting.

> **“Carers are just as important as the patient, and their fears are as much for themselves as the person they are caring for. They need their own support.”**

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Conversations for life
Support for anyone to begin end-of-life conversations.
Tel: 01539 234108
Email: info@conversationsforlife.co.uk
Website: **conversationsforlife.co.uk**

Dying Matters (Hospice UK)
Resources to help start conversations about dying, death and bereavement.
Tel: 08000 214466
Website: **hospiceuk.org/our-campaigns/dying-matters**

Hospice UK
Information about hospice care and services, and how to access them.
Tel: 020 7520 8200
Website: **hospiceuk.org**

MND Scotland
Support for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

NHS and UK healthcare
Information about NHS services and healthcare across the UK.
Website: **nhs.uk**

Tel: 111 (for urgent medical advice in England, available 24/7)
Website: **111.nhs.uk** (For England)

Tel: 111 (for urgent medical advice in Wales, available 24/7)
Website: **111.wales.nhs.uk** (For Wales)

Tel: Find individual trusts in Northern Ireland on website contact page
Website: **hscni.net** (For Northern Ireland)

Tel: 111 (for urgent medical advice, available 24/7)
Website: **nhs24.scot** (For Scotland)

Acknowledgements

With thanks to our User Review Group for kindly sharing their experiences.

Thank you also to the following for their kind review during the development or revision of this booklet:

Dr Bhavyang Acharya	Consultant in Palliative Medicine, Cynthia Spencer Hospice, Northampton.
Alison Armstrong	Nurse Consultant, North-East Assisted Ventilation Service, Newcastle upon Tyne Hospitals NHS Foundation Trust.
Professor Christina Faull	Chair of the APM Guidance and Ongoing Audit Group, Consultant in Palliative Medicine, LOROS Hospice, Leicester, and University Hospitals of Leicester.
Charlie Hardaker	Respiratory Physiotherapist and Co-Lead, Home Ventilation Service, University Hospitals Bristol and Weston NHS Trust.
Dr Christina Lloyd	Lay representative, MND Association member, and contributor to the APM Guidance.
Jonathan Palmer	Nurse Consultant in Domiciliary Ventilation, University Hospitals Plymouth NHS Trust.
Kay Phelps	Research Fellow, Department of Health Sciences, University of Leicester.
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References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

1A	NICE guideline on motor neurone disease
8A-8D	Our range of sheets about assisted ventilation and support for breathing
14A	Advance Decision to Refuse Treatment and advance care planning

Booklets

Emotional and psychological support
What you should expect from your care

Large guides

End of life - a guide for people with motor neurone disease
Caring and MND - support for you

For professionals

Motor neurone disease in acute, urgent and emergency care
A professional's guide to end-of-life care in MND
Information sheet P6 – Evaluation and management of respiratory symptoms in MND

External guidance

NICE guideline (NG42): Motor neurone disease: assessment and management:
nice.org.uk/guidance/ng42

Withdrawal of Assisted Ventilation at the request of a Patient with Motor Neurone Disease – guidance for professionals, Association for Palliative Medicine:
apmonline.org/apm-professional-guidelines

MyBreathing website - videos on ventilation and end-of-life decisions:
mybreathing.mymnd.org.uk/later-decisions

End of life decision making when home mechanical ventilation is used to sustain breathing in Motor Neurone Disease: patient and family perspectives:
link.springer.com/article/10.1186/s12904-024-01443-1

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on any of our information sheets, access our online form at:
smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or a carer, contact us at
infofeedback@mndassociation.org

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Registered Charity no. 294354

Revised: January 2026
Next review: November 2028
Version: 1