mnda
motor neurone disease
association

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Withdrawal of ventilation with motor neurone disease (MND)

Information for people with or affected by motor neurone disease

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, which is known as withdrawal of ventilation. If you have Kennedy's disease, you may also have breathing problems, but these are usually mild.

This information sheet includes:

This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

This symbol is used to highlight **quotes** from other people with or affected by MND or Kennedy's disease.

Trusted Information Creator
Patient Information Forum

This information has been evidenced, reviewed by experts and tested with users.

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):** a machine helps you breathe in normal air through a mask
- **Invasive ventilation (tracheostomy):** a tube is placed into your windpipe through the front of your neck, connected to a ventilator

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 information about breathing support, see:
information sheets 8A – *Support for breathing problems*
and 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 take place.

"Even though we sometimes fear the truth, it's comforting to read the facts. Not knowing can often create fear."

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.

"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?*
- *Further information* at the end of this sheet for other resources, including guidelines for professionals.

Whatever you decide, you can change your mind at any time.

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.

"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."

Why do early conversations matter?

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

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

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

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.

"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."

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.

What questions can I ask?

When seeking information from the professionals who support you, you may wish to ask the following questions.

Planning the withdrawal:

- How are my breathing symptoms likely to progress?
- How are my other MND symptoms likely to progress?
- How will the progression of my symptoms affect 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?
- Can I choose which professionals, family members, or spiritual leaders are present?
- 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?

“It’s not pleasant having to think about and face these things, but it’s necessary.”

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?)

“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.”

3 How is withdrawal of ventilation arranged?

If you are thinking about stopping ventilation, the first step is to discuss this with your GP, health care specialists, family and carers. Being fully informed will help you make the choice that feels right for you.

Often, these conversations lead to wider questions about planning for end-of-life. Professionals may not always raise these issues unless they sense you are ready for difficult conversations, so let them know if you would like to discuss them.

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 withdraw ventilation from an advance statement due to the risk of life.

An Advance Decision to Refuse Treatment (ADRT) is legally binding, and your wishes must be followed as long as it has been completed correctly. It allows you to refuse 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.

For more information on different types of ventilation, see:
information sheet *8B – Ventilation for motor neurone disease*

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.

> **"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."**

For more guidance on recording advance decisions and sample forms, see:
information sheet 14A – *Advance decision to refuse treatment (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.

Lasting Power of Attorney (LPA) (England and Wales): lets you appoint someone you trust to make decisions for you if you cannot. This can cover health, care and/or financial matters.

Enduring Power of Attorney (EPA) (Northern Ireland): covers financial matters only. Both are legal documents and need to be registered for a fee.

Continuing and Welfare Power of Attorney (Scotland): enables someone, or more than one person, to look after your financial affairs and health and welfare decisions.

Each of the above are 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 wider guidance about planning ahead, see:
End of Life: a guide for people with motor neurone disease

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.

“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.”

It may help to ask specific questions about any fears or worries.
See Section 2 *Who needs to be involved in discussions?* for suggested questions that may help.

Which professionals will be involved?

At least two professionals, preferably with previous 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, started 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 require advance planning and arrangements made 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 removing 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.

For further information about end-of-life planning, see:
End of life: a guide for people with motor neurone disease

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.

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

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 or not you use ventilation. 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 over a period of time. This could be hours, days or weeks.
- you may become increasingly sleepy and lose consciousness
- breathing slowly reduces and eventually stops.

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.

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, talking about death and dying can be very difficult. Thinking about the withdrawal of ventilation may bring these feelings into focus. We hope this information has helped you understand what might happen during withdrawal and to prepare for those decisions.

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.

> **“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.”**

Can anyone help me 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 the clinical setting.

6 How do I find out more?

Other organisations

We do not endorse organisations, but this list may help you search for further support. If details change before next revision, contact our MND Connect helpline (see *Our support* in this section). Find more organisations at:
www.mndassociation.org/organisations

Conversations for life

Support for anyone to begin end-of-life conversations.

Telephone: 01539 234108
Email: info@conversationsforlife.co.uk
Website: **www.conversationsforlife.co.uk**

Dying Matters (Hospice UK)

Resources to help start conversations about dying, death and bereavement.

Telephone: 08000 214466
Website: **www.hospiceuk.org/our-campaigns/dying-matters**

Health in Wales

Information on NHS services in Wales, including a directory of health boards.

Website: **www.wales.nhs.uk**

Hospice UK

Information about hospice care and services, and how to access them.

Telephone: 020 7520 8200
Website: **www.hospiceuk.org**

MND Scotland

Support and information for people in Scotland affected by MND.

Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **www.mndscotland.org.uk**

NHS and UK healthcare
Information about NHS services and healthcare across the UK.

Main website: **www.nhs.uk**

For England:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **https://111.nhs.uk**
For Wales:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **https://111.wales.nhs.uk**
For Scotland:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **www.nhs24.scot**
For Northern Ireland:
Telephone: Available via individual trusts website contact page
Website: **www.hscni.net**

Reference list

References for this information are available on request from:
infofeedback@mndassociation.org or write to:

Information feedback, MND Association
Francis Crick House, 6 Summerhouse Road
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Emma Regan, Research Fellow, Department of Health Sciences, University of Leicester

Our information resources

We have a wide range of accredited guidance, including the following. You may find these useful after reading this booklet.

1A – *NICE guideline on motor neurone disease*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

8D – *Air travel and ventilation for motor neurone disease*

14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

We also provide the following guides:

Living with motor neurone disease – our main guide to managing the impact of MND

End of life: a guide for people with motor neurone disease – our information to help you plan ahead for your future care

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

Telling people about MND – support with talking to family, children, friends and professionals

Emotional and psychological support – suggested therapies and services.

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
Website: **www.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
Website: **https://apmonline.org/apm-professional-guidelines**

MyBreathing website - videos on ventilation and end-of-life decisions
Website: **https://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
Website: **https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-024-01443-1**

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

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

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

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

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

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**

Our support

Our mission at the MND Association is to improve the lives of people with MND today, while building hope for tomorrow.

Our support is here for everyone affected by MND or Kennedy's disease, in England, Wales and Northern Ireland.

MND Connect

Our helpline team can provide emotional support, guidance and information. They can help you search for organisations, our local branches, groups and volunteers, and explain our services and grants. Interpreter calls can be arranged.

Telephone:	**0808 802 6262**
Email:	**mndconnect@mndassociation.org**

Support services

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

Local and regional support

Find out about our branches and groups, at:
www.mndassociation.org/local-support

MND Association Benefits Advice Service

Explore benefits for England, Wales and Northern Ireland, with professional advisers. Find contact details and more at:
www.mndassociation.org/benefitsadvice

MND Association website

Find out about our work and how to get involved with membership, fundraising and campaigning at: **www.mndassociation.org**

MND Association online forum

Share experiences with others affected by MND or Kennedy's disease. View posts or become a member and join chats at: **https://forum.mndassociation.org**

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you feel we did well and how we can improve this content for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding.

Find our feedback form at: **www.smartsurvey.co.uk/s/infosheets_1-25**
Email your comments to: **infofeedback@mndassociation.org**

Or write to:

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