

8C

Withdrawal of ventilation with MND


Information for people with or affected by motor neurone disease

MND can affect your breathing muscles as the disease progresses and you may be referred to a respiratory team (breathing specialists). They will explain the support available and you may choose to accept help from a machine with your breathing. This is known as ventilation. Over time, you are likely to become reliant on ventilation, so you need to be fully informed about your choices. Ventilation support can improve quality of life and may prolong survival, but it cannot reverse the disease or stop it from progressing.

As speech and communication can also be affected by MND, ask your health care professionals for further detail as early as you can, in case discussion becomes more difficult. It's also important to make them aware of your views and preferences. If you become reliant on ventilation support, you can still choose to stop using it, which is known as withdrawal.

Professional support is needed to withdraw ventilation and this information sheet explores how this is done:

- 1: Why do I need to think about withdrawal of ventilation?**
- 2: Who needs to be involved in discussions?**
- 3: How is withdrawal of ventilation arranged?**
- 4: What happens when ventilation is withdrawn?**
- 5: What support can be provided?**
- 6: How do I find out more?**

 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.

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

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

Please note the content in this information sheet includes sensitive details about end of life decisions. Reading about this may feel difficult, but may help you make timely choices and communicate your wishes.

Mechanical support to help you breathe is known as ventilation. The two main types are:

- **Non-invasive ventilation (NIV)**, where a machine supports your breathing by helping to improve your intake of normal air through a mask.
- **Invasive ventilation** (also known as a tracheostomy), where a tube is inserted into your windpipe through the front of your neck, enabling a ventilator to take over your breathing.

If you develop breathing problems with MND, ventilation can help ease certain symptoms, such as fatigue, and may prolong survival.



For more information about breathing support with MND, see:
Information sheets 8A – *Support for breathing problems*
and 8B – *Ventilation for motor neurone disease*

Extending life in this way may be what you wish to happen. It may be something you want to avoid. Your views may change over time, but being informed helps you feel prepared.

It is important to note that other symptoms will continue to get worse, with or without ventilation support. This may raise questions about quality of life and how your future care will be managed.

You can stop using ventilation at any point, if you wish, or continue using ventilation for as long as you want to – the choice is yours.

As breathing becomes weaker, you may need to rely more on your ventilator, whether using NIV or invasive ventilation. Becoming reliant means you will no longer be able to breathe effectively without the help of the machine, which means your life is at risk if you stop using it. Removal of ventilation in these circumstances is known as withdrawal and it can be helpful to understand how this would be managed.



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

What are my rights?

If you decide to use ventilation, you can continue using it for as long as you wish. You do not have to stop using ventilation, unless you choose to do so.

If you do not wish to use ventilation at all, you do not have to start using it, even if you develop breathing difficulties.

If you use ventilation, but wish to stop, you can do this at any point. This means your mechanical breathing support can be removed and your symptoms managed in a different way. **This is your legal right, even if you have become reliant.**

It's important to understand your life is at risk if you choose to withdraw ventilation after becoming reliant. At this point, it has become a life-sustaining treatment, but you may reach a point where you feel a treatment has become a burden, or no longer helpful. If this is the case, it is legally acceptable to have ventilation removed, even if a natural death is the likely outcome.



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

Withdrawal of a life-sustaining treatment at your request is **not** the same as assisted dying. With assisted dying, a health care professional would have to deliberately attempt to hasten or speed up the process of death. This is illegal under UK law, but withdrawal of treatment is allowed.

Many professionals may not be experienced in withdrawal of ventilation in MND and some may feel overwhelmed or unsure about the laws governing withdrawal. In some cases, they may even refuse to help if they worry it may be confused with assisted dying. If this happens, ask for referral to a specialist palliative care team.

It may feel difficult at first, but having early conversations about this subject can help ensure:

- you get the support you need, in the way you wish
- plans are made in a timely way, to avoid rushing decisions at a later stage
- your wishes are respected, even if you become unable to make decisions or communicate for any reason (this may require written instructions).

These conversations also let professionals know that your views and wishes are informed, and that you are settled in your choice. This is important, as they can find these decisions difficult too. They need to ensure you have taken into account both the burdens and benefits of continuing ventilation, and the consequences of stopping it.

See Section 3: *How is withdrawal of ventilation arranged?* for more details about writing instructions for future care, known as advance decisions.



“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.”

Health care professionals have a duty to help you feel fully informed about any medical intervention. This includes the introduction, management and possible withdrawal of treatments, including ventilation or tube feeding. **Whatever you decide, you can change your mind at any time.**



For publications about planning ahead, including guidelines for professionals, see: *Further information* at the end of this sheet.

2: Who needs to be involved in discussions?

To manage your future care, your wishes need to be communicated to those involved. This includes possible decisions about withdrawal of treatments. Family members, carers, and supporting 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.”

It can be tempting to avoid difficult conversations until a later date. However, it may become increasingly difficult to have effective or complex conversations if your MND symptoms cause:

- fatigue
- problems with speech and communication
- changes to the way you think and process information (up to half of people with MND may experience some changes to thinking, although this is usually mild).

Conversations about future care can be emotional and your family and carers may have different views. If this happens, ask your supporting health and social care professionals to help. They can explain your options in full, and answer questions and 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.”

Open discussion can help professionals too, who may also find this an emotional subject. Discussion with relevant professionals, such as palliative care and respiratory specialists, is important to ensure best possible support.

If you have an MND co-ordinator at an MND care centre or network, or a specialist nurse at a neurological clinic, they should be able to refer you to a palliative or respiratory expert with appropriate experience and knowledge.

What questions can I ask?

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

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 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 ensure they have appropriate experience?
- Where can the withdrawal happen?
- Can I request for specific professionals to be present?
- Can I have a chosen spiritual, religious or faith leader with me during the withdrawal process?
- Can I request for members of my family or close friends to be with me during the withdrawal process?
- Who will support my loved ones, especially if I rely on ventilation and 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 withdraw ventilation, how will my symptoms and anxiety be managed, especially if I have become reliant?
- Can you explain exactly what will happen and how long each action is likely to take?
- Will I be in any pain?
- Will I experience any sensation of gasping or choking?
- If I change my mind during or after the withdrawal, can I be placed back on ventilation?
- Will I still be aware and able to communicate any change of mind or distress (or helped to communicate if using communication aids)?



"If you, or your carer, has a religious faith, it can be helpful to discuss all aspects of ventilation and its possible withdrawal with your faith leader."

3: How is withdrawal of ventilation arranged?

If you are thinking about withdrawing ventilation, discuss this first with your GP, health care specialists, family and carers. Being fully informed is the first step.

Discussion about withdrawal of ventilation usually leads to wider exploration of end of life decisions. However, your professionals may not raise points like this with you, unless they sense you are ready for these difficult conversations. If you want to discuss any aspect of future care, let them know.

As there is risk to life when withdrawing ventilation (where you have become reliant), your mental capacity will be assessed as part of the decision making process.

Mental capacity is your ability to make choices and decisions on your own behalf.

This is governed by the **Mental Capacity Act 2005**, which involves five main principles:

- that you are believed to have capacity unless clearly proven otherwise
- that you are not to be treated as unable to make a decision, unless all practical steps have been taken to help you without success
- that you are not to be treated as unable to make a decision simply because you make an unwise decision
- that if you are without capacity, anything done for you must be in your best interests
- that if you are without capacity, any decision on your behalf should be the least restrictive of your basic rights and freedoms.

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

Withdrawal can then be planned as you wish, either in the near future or at a later stage. As your illness progresses, the professionals working with you will help you review or revisit your decisions to consider if you are settled in your view.

How do I make an advance decision?

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



"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 misunderstanding."

An advance statement of your wishes can be placed in your records, such as general advance care planning, or end of life planning. This could include notes about withdrawal of ventilation.

These wishes will only be used if you become unable to communicate or make decisions for yourself.

However, an advance statement is not legally binding. It guides professionals about your wishes, but they do not have to follow them. Some professionals may find it difficult to agree to withdrawal of ventilation from an advance statement, due to the risk to life. If you want to ensure your choices are followed, use an Advance Decision to Refuse Treatment (ADRT). This allows you to record decisions in advance, but is legally binding. Your wishes must be followed, as long as the ADRT has been completed correctly.

In an ADRT, you need to be clear which treatments you want to refuse or withdraw in the future, and the precise circumstances of when to not use or stop using such treatments. You also need to sign to show you understand the risk to your life.

Give a copy of your ADRT to all involved in your care, so they are aware of your wishes. Keep the original safe, but easy to find and access in an emergency (not locked away).



"I have discussed my ADRT with my partner and relatives, but I'm about to discuss it with a few close friends who will be able to give my partner support when the time comes, as my relatives live abroad."

An ADRT is:

- only usable if completed correctly
- only used if you are unable to make decisions or communicate
- legally binding if correct, which means your wishes must be carried out if you become unable to communicate or make decisions on your own behalf.

You can change your mind and review the content of your ADRT at any time, if required. It is important to keep the ADRT up-to-date. If you have done something since writing the ADRT to suggest you no longer hold the same views, doctors may have doubts about whether decisions in the document are valid.



For more detail about how to record advance decisions, see: Information sheet 14A – *Advance Decision to Refuse Treatment* which includes a sample completed ADRT form and a blank form to use if you wish.



For wider guidance about end of life decision making, see: *End of life: a guide for people with motor neurone disease*.

You can also use an ADRT to stop new treatments being introduced, if unwanted – this is what is meant by 'refusal' of treatment.


For example, invasive ventilation (tracheostomy) can be introduced during emergency treatment or resuscitation, without your prior agreement. With MND, it can then be difficult to stop using this support after the emergency is over. This has implications for your future care, as you will become more dependent on others as symptoms progress. Sometimes, invasive ventilation may mean moving into a nursing home for the clinical care that is required. If you do not want invasive ventilation introduced (or other treatments), even in an emergency, be specific about this in your ADRT.

Is there any other way someone can make decisions for me in the future?

All efforts should be made to help you communicate your own wishes. This may mean 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.

You can legally appoint one or more representatives (this could be a family member, friend or professional) through Lasting Power of Attorney in England and Wales. This can cover financial or health care matters, or both. In Northern Ireland, you can use an Enduring Power of Attorney (EPA), but this can only cover financial matters.

An LPA or EPA is a registered legal document, which means a fee will be charged.

 For more details about LPAs and EPAs, see:
End of life: a guide for people with motor neurone disease.

4: What happens when ventilation is withdrawn?

Unless fully reliant on ventilation to breathe, you may still be able to breathe on your own if your mask is removed. However, as MND is a progressive disease, your symptoms get worse over time, so your breathing is likely to be weaker than before you started using ventilation. When you stop using it, you will be supported to help manage difficulties, such as breathlessness or anxiety. This usually includes the use of medication which is started before the ventilation is stopped.

The professionals helping you with ventilation withdrawal need to ensure you understand the possible risk to life.

If you have become reliant, a natural death is likely to follow the withdrawal in a relatively short space of time. This space of time is difficult to predict, so could be as quick as 15 minutes, or may be a few hours or occasionally a day or so. Again, you will be given support to manage any symptoms that arise.



"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 will need to be with you to support and advise during the process. The following professionals are recommended, preferably with previous experience of ventilation withdrawal:

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

Other professionals may need to be informed about what is happening, so they can support you and your family before, during or after the withdrawal. This will include your GP and any care workers that help with personal care.



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

What steps are taken to withdraw ventilation?

The process of withdrawal will usually include the following:

- information sharing and discussion between everyone involved
- preparation and planning, including arrangements for the professionals who will support you
- symptom management using medications, both before and during the withdrawal
- testing that symptoms are well managed before fully withdrawing ventilation support
- withdrawal of ventilation, with medication to minimise any distress
- support for family or friends, if present.

Arrangements may take some time, especially if the withdrawal is to take place at home. It is important that the right equipment, medication and professional support are all available. If you want certain family members or friends with you, they may also need to make arrangements or travel.

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 make sure 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 ahead to enable your preference. Having your wishes written down will be helpful.



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

Family members or friends should not be expected to take part directly in the withdrawal of equipment, unless they ask to be involved (such as removing an NIV mask). This should be discussed with the supporting health care professionals in advance, so that any possible emotional impact can be considered.

Family or friends present at the withdrawal are also recommended to seek follow-up discussions with professionals, to help manage emotions after the withdrawal.

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

It can help to reduce fear if you know what to expect. 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 weakness of the breathing muscles. This weakness is usually the cause of death with MND, whether or not you use ventilation. The following may help to explain how this happens.

Breathing muscles weaken gradually with MND, but this usually becomes more apparent during the final stages of the disease. Over a period of time, which can be hours, days or weeks, your breathing is likely to become more shallow. This usually leads to increasing sleepiness and reduced consciousness. Death comes peacefully, as breathing slowly reduces and eventually stops.

In some cases, lips and hands can look a little blue in colour when the person is dying, as oxygen levels reduce. At this stage, the person is usually unconscious and unaware. It can be worrying to family or friends who are present, so it may be useful for them to know this might happen.

Sometimes the breathing pattern can change just before death, with previously deeper breaths becoming much more shallow. In most cases, people with MND have a peaceful death.

When breathing becomes weaker, you may feel breathless and this can be distressing, but you will be supported with medication to reduce breathlessness and anxiety. With planned withdrawal of ventilation, this can be carefully managed.

Medication to manage symptoms may make you feel even sleepier. If this happens, you may not be fully aware of people and events around you. It helps for you and your family to be prepared for this. However, medication can usually be adjusted to find a level that works best for you.

5: What other support can be provided?

For many people, death is a difficult subject to discuss or think about, and withdrawal of ventilation brings this into focus. We hope this information has helped you understand what might happen during withdrawal and in the final stages.

We also recognise that you may feel overwhelmed when thinking about end of life. You, your family and carers may find it helpful to discuss any concerns.



“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.”

Your GP, your specialist palliative care professionals, and other health and social care professionals can offer support and advice.

If you have an MND Association visitor, they can listen and offer reassurance. You can also contact our MND Connect helpline if you have any questions, or need emotional support. See *Further information* in section 6: *How do I find out more?* for contact details.

Knowing what to expect may help to make conversations about dying feel less frightening.

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.

6: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Conversations for Life

Help for families, professionals and communities to start discussions about end of life care.

Address: 2 The Mill Yard, Staveley, Cumbria LA8 9LR
Telephone: 01539 234108
Email: info@conversationsforlife.co.uk
Website: www.conversationsforlife.co.uk

Dying Matters

Hosted by Hospice UK, with help to start conversations more easily about dying, death and bereavement.

Telephone: 08000 21 44 66
Email: through the website contact page
Website: www.hospiceuk.org/our-campaigns/dying-matters

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards. This is an online information service only (see also NHS Direct Wales).

Email: through the website contact page
Website: www.wales.nhs.uk

Health and Care Professions Council (HCPC)

A regulatory body who keep a register of health professionals who meet their standards of practice.

Address: Park House, 184 Kennington Park Road, London, SE11 4BU
Telephone: 0300 500 6184
Website: www.hcpc-uk.org

Hospice UK

Information about hospice care and services, and how to get referred.

Address: Hospice House, 34-44 Britannia Street, London WC1X 9JG
Telephone: 020 7520 8200
Email: through the website contact page
Website: **www.hospiceuk.org**

MND Scotland

For guidance about MND support if you live in Scotland.

Address: Unit 8, 76 Firhill Road, Glasgow G20 7BA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **www.mndscotland.org.uk**

NHS (online)

Online information to help you make informed choices about health.

Telephone: 111 for urgent, but non-emergency medical advice 365 days a year
Website: **www.nhs.uk**

NHS 111 Wales

Health advice and information service for Wales.

Telephone: 0845 46 47 for urgent, but non-emergency medical advice,
or 111 if available in your area
Website: **<https://111.wales.nhs.uk>**

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service.

Email: through the website contact page
Website: **<http://online.hscni.net/other-hsc-organisations>**

References

References used to support this information are available on request from:

email: **infofeedback@mndassociation.org**

Or write to: Information feedback, MND Association, Francis Crick House,
Summerhouse Rd, Moulton Park, Northampton NN3 6BJ

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Acknowledgements

Many thanks to the following for their expert guidance with this information sheet at development or revision:

Dr Bhavyang Acharya, Consultant in Palliative Medicine, Cynthia Spencer Hospice, Northampton.

Professor Christina Faull, Chair of the APM Guidance and ongoing audit group, and Consultant in Palliative Medicine, LOROS Hospice, Leicester and University Hospitals of Leicester.

Dr Christina Lloyd, lay person and representative member of MND Association for the APM Guidance.

Kay Phelps, Research Fellow, Department of Health Sciences, University of Leicester.

Emma Regen, Research Fellow, Department of Health Sciences, University of Leicester.

Further information

You may find some of our other information useful in relation to this sheet:

Information sheets

1A – *NICE guideline on motor neurone disease*

8A - *Support for breathing problems*

8B - *Ventilation for motor neurone disease*

8D - *Troubleshooting for non-invasive ventilation (NIV)*

8E - *Air travel and ventilation for motor neurone disease*

14A - *Advance Decision to Refuse Treatment (ADRT)*

Guides

Living with motor neurone disease – our guide to MND and how to manage its impact.

End of life: a guide for people with motor neurone disease – our information about end of life decision making, including details about withdrawal of life-sustaining treatment.

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND.

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

Telling people about MND – support on how to discuss your condition and raise awareness of your needs with family, children, friends and professionals.

Emotional and psychological support – suggested support and therapies.

Relevant publications for professionals

Our titles include:

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 motor neurone disease

External publications include:

NICE guideline (NG42) *Motor neurone disease: assessment and management* This guideline sets out recommendations to professionals for the treatment and care of MND, including planning for end of life. See: www.nice.org.uk/guidance/ng42

Withdrawal of Assisted Ventilation at the request of a Patient with Motor Neurone Disease
Guidance for professionals: published by the Association for Palliative Medicine of Great Britain and Ireland. <https://apmonline.org/apm-professional-guidelines-2>

MyBreathing – this website has videos on experiences with ventilation, including decision making about end of life. See:

<https://mybreathing.mymnd.org.uk/late-decisions>

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support:

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: www.mndassociation.org

Online forum: <https://forum.mndassociation.org/> or through the website

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

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

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

Created: November 2021
Next review: November 2024
Version: 1

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