



8B

Ventilation for motor neurone disease (MND)

Information for people with motor neurone disease (MND) and their carers

If MND affects your breathing, a machine can help you breathe more easily. This is called assisted ventilation, and this information sheet explains the options and how they can help. It covers:

- 1 What is assisted ventilation and how can it help?**
- 2 What do I need to know about non-invasive ventilation (NIV)?**
- 3 What do I need to know about tracheostomy ventilation?**
- 4 How do I look after my ventilation equipment?**
- 5 What do I need to know about withdrawal of ventilation?**
- 6 How can I find out more?**



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



This symbol is used to highlight quotes from other people with or affected by MND.



This information sheet has been endorsed by the Association of Chartered Physiotherapists in Respiratory Care (ACPRC).



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

What do the words mean?

You may hear these words used by professionals.

assisted ventilation	A machine to help you breathe.
BiPAP	BiPAP stands for 'Bilevel Positive Airway Pressure' and is a type of non-invasive ventilation. Some people use this name instead of NIV.
dependent or reliant	With ventilation, this means needing to use a ventilation machine for more than 14 hours in every 24 or being unable to breathe effectively without it.
mouthpiece ventilation (MPV)	A form of NIV where you use a straw-like nozzle to get a boost of air into your lungs as needed. Ask your respiratory team if you think it may be useful.
non-invasive ventilation (NIV)	A type of assisted ventilation, where the machine boosts the flow of normal air into your lungs. This is usually through a nose or face mask held on by straps around your head.
tracheostomy	A surgical procedure to make an opening in the front of your neck, where a tube can be inserted into your windpipe. This can then be used for ventilation.
trache ventilation (tracheostomy ventilation)	A machine that supports breathing, by sending air through a tube inserted into your windpipe through your neck. The full name is tracheostomy ventilation. For ease of reading, the shortened version of trache ventilation is used in this sheet. This is also known as invasive ventilation.
respiratory care or management	This type of care provides assessment of your breathing, support and therapies.
respiratory team	Health professionals who specialise in support for breathing.
secretions	With breathing support, this refers to mucus or saliva.

This sheet includes sensitive topics, such as withdrawal of ventilation and planning for future care. Read when you feel ready to do so.

1 What is assisted ventilation and how can it help?

With MND or Kennedy's disease your lungs can still process air, but you may find it gets harder to breathe air in and out. This is because the muscles you use to breathe can weaken.

Breathing support is available, which includes help from a machine that supports the flow of air into your lungs. This type of machine is called assisted ventilation.

We shorten this to ventilation in this sheet and there are two types:

- **Non-invasive ventilation:** this machine boosts the flow of normal air into your lungs. This is usually through a nose or face mask held on by straps around your head.
- **Trache ventilation:** this machine supports breathing by sending air through a tube inserted into your windpipe, through your neck. The full name is tracheostomy ventilation, also known as invasive ventilation.

Either type of ventilation can help ease a number of symptoms, improve quality of life and may prolong survival.

However, ventilation cannot stop or reverse the way each disease progresses. Your breathing will continue to weaken, and you are likely to become dependent on ventilation over time.

There is a lot to think about, but this guidance may help you in discussions about ventilation. It explores general information and what you need to know about each type.



For an overview of general breathing support, see:
information sheet 8A – *Support for breathing problems*

Does ventilation involve extra oxygen?

In most cases, ventilation uses normal air to help you breathe.

Extra oxygen is not usually recommended with MND, as it can upset the balance between oxygen and carbon dioxide in your body. However, oxygen may still be used if you have a chest infection, other lung condition or need temporary support.

This should be done under medical supervision, with healthcare professionals who know and understand your diagnosis.

When should I start thinking about ventilation?



“Forewarned is forearmed to what may lie ahead. I always feel it’s better to know what’s ahead and ways of dealing with it. The unknown is always more frightening.”

Find out as much as you can before breathing symptoms become severe. Ask a member of your healthcare team for referral to a respiratory team, who can guide you through:

- the types of ventilation available
- the benefits and possible challenges of each option
- how your needs may change over time
- what care is like after ventilation is introduced
- what is likely to happen if you decide to stop using ventilation (known as withdrawal)
- any other questions you may have.

Your decision will depend on:

- your personal views, needs and wishes for your future care
- whether ventilation is suitable for you
- when it’s best to start using it.

Being informed can help you discuss options with your family, carers, and health professionals. Doing this as early as possible gives everyone time to understand your preferences and prepare the right care in advance.



“My own experience has shown that people are not always prepared early enough. Or symptoms have not been spotted early enough. In my husband’s case, his breathing problems were too far advanced for him to use non-invasive ventilation effectively.”

Your respiratory team can guide you on how ventilation can be used, which may be part-time at first. Early planning can help avoid the need for emergency decisions, which may not enable the choices you want.

What are the early signs I may need ventilation?



“When I visit the MND clinic every three months I have a vital capacity test and a cough test. I am sure my care team would step in and give me advice and recommendations as and when they observed my lung capacity declining to a worrying level.”

Weakened breathing muscles can lead to:

- breathlessness, even when resting
- shallow breathing, especially when lying flat
- a weak cough and trouble clearing mucus or phlegm
- repeated or long-lasting chest infections
- a weak sniff
- poor sleep, disturbed by breathing difficulties
- feeling tired when you wake up or throughout the day
- morning headaches
- vivid dreams or nightmares
- feeling confused, forgetful or unable to concentrate
- a weaker voice
- reduced appetite or weight loss



For more on breathing symptoms and tests, see:
information sheet 8A – *Support for breathing problems*

If weakened breathing affects how you speak and communicate, ask for referral to a speech and language therapist for assessment, and guidance on speech therapy and communication aids.



For more on speech and voice support, see:
information sheet 7C – *Speech and communication*
information sheet 7D – *Voice banking*

Your speech and language therapist can also assess any swallowing difficulties. This matters as you may find food and drink ‘goes down the wrong way’ into your airways, known as aspiration. If your breathing is weak, it can get harder to cough and clear your throat, and aspiration can cause repeated chest infections.



For more about swallowing and coughing, see:
information sheet 7A – *Swallowing difficulties*

You can get help to cough, including:

- support from your health and care team
- techniques you can learn to apply yourself
- a machine that helps you cough more effectively.

Ask your GP about getting the annual flu vaccine, and the pneumonia and Covid vaccines to reduce the risk of getting these. That helps prevent severe chest infections. Ask your GP if your main carer and close family members can also get these vaccinations.

What happens if I become dependent on ventilation?

Becoming dependent on ventilation means you can no longer breathe well without it. This can happen with either type of ventilation, but the timing varies from person to person depending on your symptoms and the type of ventilation you use.

As your muscles weaken, your own breathing may not be strong enough to trigger the machine. Most ventilators can detect this and take over by delivering breaths automatically after a set period of no breathing.

If the ventilator is providing all of your breaths and you no longer trigger it, this is known as being fully ventilated.

Eventually, as your breathing needs increase, you may need 24-hour support. If you choose to stay at home, a care package is usually needed. Even with strong family support, this usually includes trained care workers.



“I sleep on a daybed beside him so that I am on hand quickly when he needs his secretions suctioning in the middle of the night. I can’t leave him alone in the room at any time.”

Some ventilators include built-in alarms to raise an alert if you need help. This may be necessary if your speech and communication are affected.

Ask your health and social care team for guidance on devices or systems that call for help, how they work and if someone needs to be present in your home to respond quickly.

How can my carer get support if I become dependent on ventilation?

Family members and unpaid carers often need practical guidance and training as your needs become more complex. Especially if your breathing is affected and you use ventilation. They may also need emotional support, and respite breaks for rest or other needs away from home.



“We have a nurse who comes once a week to be with him so I can go and do a shop or go to any appointments. The rest of the time I am pretty much confined to the house. I’m not even able to hang the washing out as I wouldn’t be able to hear any of his emergency alarms indicating a problem.”

Because care with breathing needs can be intensive, some areas may only offer full home support with specialist care packages and funding.

In complex cases that need medical help, moving into a nursing home may be suggested. This varies across regions, so ask your respiratory team to understand what’s available in your area.

Can I choose whether or not to use ventilation?

Yes. It is your decision whether to use ventilation or not. Everyone has different feelings about how they want to manage their condition. Some people adjust to increasing disability and wish to extend life for as long as possible.

However, you may wish to make a different choice based on your preferences and beliefs.



“It’s important to know that ventilation can increase life expectancy with MND as, in our case, my husband did not want to extend his life.”

There is no right or wrong answer, and your decision should be respected. Discussing through all the support options with your team can help you make a choice that feels right for you.

If you choose not use ventilation, there are still other ways to ease breathing symptoms. Your respiratory team, physiotherapist, or palliative care team can help you find the right support. This might include:

- breathing exercises
- help to clear your chest and cough
- guidance on posture and positioning
- relaxation techniques
- talking therapies or counselling
- medication to ease breathlessness or anxiety.



For more on other breathing therapies, see:
information sheet 8A – *Support for breathing problems*.

Whilst therapies or ventilation can help you feel more comfortable; they won't slow the progress of the disease. Over time, breathing problems do get worse as muscles continue to weaken.



For more about future care and the later stages of MND, see:
our guide on *End of life: for people with motor neurone disease*.

2 What do I need to know about non-invasive ventilation (NIV)?

Non-invasive ventilation (NIV) is the most commonly used form of ventilation for people with MND. It helps your breathing by gently boosting the flow of air in and out of your lungs.

This is usually done through a mask that fits over your nose, or both your nose and mouth.

Several types of masks are available. If you find they are uncomfortable or difficult to manage, nasal pillows may be an option. These are soft tubes that sit just inside the nostrils and are held in place by head straps.



“Wearing my [NIV] ventilator 24 hours a day allows me to lead what I call a ‘normal’ life and doesn’t stop me from doing what I want to do.”

Your mask connects by tubing to the ventilator machine, which is powered by electricity, battery or both.

When you breathe in, ventilation provides a boost of air to help you breathe more effectively.

Your mask and ventilator settings can be adjusted to meet your needs. This is usually done as an outpatient in hospital, but some services may offer home visits if you find it hard to travel.

You can also make some minor adjustments at home, such as the way the mask straps fit. You will be given guidance on what you or your carer can do.

Some ventilator settings can be adjusted remotely by your respiratory team, even if you live a long way from the nearest hospital.

Ask your healthcare team about the equipment and support available in your area.



“My NHS NIV pump sends data to my ventilation team for analysis. Based on the findings, they can adjust any of the settings – including how humid the air is!”

What do the NICE guidelines say about NIV?

The National Institute for Health and Care Excellence (NICE) produces guidelines to help health and social care professionals supporting specific conditions.

Guideline NG42 for the management of motor neurone disease recommends NIV to support breathing impaired by muscle weakness.



For more information on the NICE guideline, see:
information sheet 1A – *NICE guideline on motor neurone disease*
or our pocket booklet - *What you should expect from your care*

Possible benefits with NIV

For most people, NIV helps by:

- easing symptoms like shortness of breath, disturbed sleep, tiredness and morning headaches
- improving quality of life and energy levels
- extending survival time
- giving breathing support without the need for surgery
- making part-time use easy in the early stages of MND
- offering a range of masks to find the most comfortable fit
- giving more volume to your voice if it has become weak
- enabling ease of moving around at home or when travelling, with use of a battery.



For more information on travelling with ventilation, see: Information sheet 8D – *Air travel and ventilation* and our *Getting around* booklet.

Things to think about with NIV

NIV may cause:

- air leaks around the mask leading to eye irritation or skin soreness from the pressure of the mask
- anxiety if you are claustrophobic
- a dry mouth, or a blocked or runny nose
- an increased risk of food or drink getting into your airways when eating or drinking (aspiration)
- more air to be swallowed than usual, making you feel full or bloated
- some discomfort while getting used to how it feels and the flow of air
- increased care needs when relying on NIV in the later stages of MND
- changes to the rhythm of natural speech
- some noise from the machine, which although low level may take time to adjust to, especially for anyone else in the same room.

What aftercare is needed with NIV?

Your respiratory team can help you adjust to using the equipment. Everyone's needs are different, but aftercare may include:

- adjusting the mask or straps to improve comfort or reduce air leaks, including using different masks in rotation
- learning cough techniques or how to use a machine to help you cough, so that you can clear mucus or saliva
- using eye drops if air leaks cause dryness or irritation
- adding a humidifier to the ventilator to add moisture to the air flow and reduce a dry mouth or blocked nose
- drinking more fluids to help with dry mouth, thick or sticky saliva and constipation (some people find pineapple juice helpful)
- advice from a speech and language therapist on swallowing and communication
- asking your team to adjust your ventilator to reduce bloating from swallowed air
- gentle movement or assisted repositioning to help trapped air pass through your system (some people find peppermint water helpful)
- support for any feelings of anxiety or panic.



For more details, see:

information sheet 7A – *Swallowing difficulties*

information sheet 7C – *Speech and communication support*

The following section contains information about planning for future and end of life care. Read when you feel ready, but it may help when making informed choices about ventilation.

What happens over time with NIV?

At first, you may only need to use NIV at night. This can help improve your breathing, quality of sleep and how you feel during the day. Over time, as the disease progresses, you might need to use it during the day as well, to help relieve symptoms.



“I started just using NIV for an hour each day and slowly increased my use, so I found it easy when I needed to use it all night.”

Eventually, you may become dependent on NIV. This means you need to use it all the time as you won't be able to breathe on your own. Everyone's experience is different and the time it takes for this to happen varies. If it does, you will need:

- a back-up ventilator in case one breaks
- a machine that can run on battery power in case of power cuts
- additional care support, including overnight help.



See Section 4 *How do I look after my ventilation equipment?* for tips on what to do during a power cut.

3 What do I need to know about trache ventilation?

Trache ventilation (tracheostomy ventilation), supports breathing by sending air through a tube into your windpipe. The tube is inserted into a small opening made in the front of your neck.

The tube is connected to a ventilator machine, which runs on electricity, battery power, or can run on either. As well as supporting your breathing, trache ventilation can also be used to clear secretions from your airways.

To have the tube fitted, you need a surgical procedure. This is usually done under general anaesthetic, so you are asleep during the operation.

After surgery, you'll need to stay in hospital while your care team plans how to support you at home or in another setting.

It is important to have conversations about trache ventilation with your family, carers, and health and social care team before you make any decisions.



“Despite general caution about invasive ventilation, I decided to proceed with a tracheostomy after deliberations with my family and extensive reading of research papers.”

When might trache ventilation be considered?

Trache ventilation is not always offered to people with MND in the UK. Ask your respiratory team for guidance in your area.

Trache ventilation may be suggested if:

- NIV is no longer comfortable or effective
- you have very weak mouth and throat muscles
- you have lots of secretions that are hard to manage
- you've had a severe chest infection that requires more extensive suctioning.

Possible benefits with trache ventilation

For most people, trache ventilation helps by:

- easing symptoms like shortness of breath, disturbed sleep, tiredness and morning headaches
- improving quality of life and energy levels
- extending survival time
- providing support if NIV no longer works well
- managing secretions
- avoiding the need for a face mask if you experience claustrophobia.

Trache ventilation can also be portable if powered by battery. For example, when using a wheelchair.



For information on flying with ventilation, see:
information sheet 8D - *Air travel and ventilation*



“Despite some inconveniences and discomfort (more from coping with being bedridden rather than the tracheostomy itself), I have enjoyed life, and never regretted the decision, nor have my family.”

Things to think about with trache ventilation

A tracheostomy procedure carries some risk of infections or complications, like any surgery. These will be explained to you before the procedure, and in most cases can be easily managed.



“I was a very active and busy man. With trache ventilation, I’ve had to adapt to a very different way of life, including being far more attentive to family and friends, and more reflective. I’ve also become an expert in films.”

You may need a long stay in hospital after the operation, while your after-care plan is organised. This can sometimes take months to organise. Care for a tracheostomy can be difficult and may mean training a team of people (usually through a care agency).

In some areas, this level of care may only be offered if you move into a nursing home. Discuss this with your respiratory team, who can advise on the situation in your area.

If you are thinking about trache ventilation, it is essential to discuss this with anyone likely to be involved in your future care. This includes family and close friends.

Trache ventilation may:

- cause discomfort or long-term damage in the windpipe from the tube (this is uncommon)
- need changing regularly, usually every month
- be uncomfortable when having the tube changed, but your respiratory team can advise on this
- affect your ability to speak or swallow, depending on the type of trache used, but your speech and swallowing may already be affected with MND (support can be given to help you communicate, eat and drink)
- cause secretions to build up which have to be cleared regularly using suction (this can be uncomfortable, as it is done while you are off ventilation)
- increase the risk of bacteria or infection in the lungs, which needs monitoring and care
- take time for you to get used to the equipment and how it feels.



For more about eating, drinking and communication, see:
information sheet 7A – *Swallowing difficulties*
information sheet 7A – *Tube feeding*
information sheet 7C – *Speech and communication support*.

The following section contains information about how the disease will progress. Read when you feel ready, but it may help when making informed choices about trache ventilation.

What happens over time with trache ventilation?

If your breathing muscles are already very weak from MND, you are likely to become dependent on trache ventilation straight away. This means the machine will be doing all of the work to help you breathe.



“Together, seven years on, we have seen our children grow into young adults, get married and we have become grandparents to two beautiful babies. So there have been some amazing highs while he has been on trache ventilation, but there have also been so many days in between them which have been really hard.”

Once you are dependent on it, it's usually not possible to return to breathing without this support. However, it is your right to stop using ventilation if that is your choice.



See Section 5 *What do I need to know about withdrawal of ventilation?*

Trache ventilation can help prolong survival, but as with NIV, your other symptoms will continue to progress. This means:

- increased risk of chest infections which maybe serious or life-threatening
- continued weakening of muscles used for swallowing, speaking and communication
- more complex care needs over time, requiring regular suctioning and support with eating, drinking and hygiene.



“In our case, speech, eating and drinking became impossible for my husband when he had a tracheostomy.”

These changes can affect how you want to be cared for in the future, so it's important to have open conversations with your family and care team about your wishes.



For ways to record your preferences for your care and treatment, see how to plan ahead in Section 5 *What do I need to know about withdrawal of ventilation?*

You'll also need to plan carefully for power cuts or equipment problems. This means having:

- a battery-powered ventilator with fully charged batteries
- a spare machine in case the main one stops working.



For more about what to do during a power cut, see:
Section 4 *How do I look after my ventilation equipment?*

Can I avoid being fitted with a trache in emergency situations?

It's possible that trache ventilation may be introduced without your prior consent. This could happen if you need urgent support and you're unable to tell medical staff your preferences. For example, during an emergency, this type of ventilation is sometimes used to stabilise breathing.



“He was rushed into hospital as he was having breathing difficulties caused by a severe chest infection. He had a tracheostomy, as it was hoped that he would be able to support his own breathing, but this was not the case, and he has been on a ventilator ever since.”

If you feel strongly that you don't want trache ventilation in any circumstance, you can record this in a document called an *Advance Decision to Refuse Treatment (ADRT)*. This can guide your team and is legally binding if completed correctly.



For more on planning ahead, see:
Section 5 *What do I need to know about withdrawal of ventilation?*

What aftercare is needed with trache ventilation?

Ongoing aftercare with trache ventilation is essential to keep you safe, comfortable and well supported. What you need can vary, but often includes:

Air humidification: the ventilator air may need to be warmed and moistened using a humidifier, which can be attached to your machine. This helps to prevent your airway and lungs from becoming dry or irritated.

Clearing secretions: you may need help clearing mucus or saliva from your airway. This could involve:

- regular suctioning by machine, but your respiratory team will guide you and your carers on how to do this safely
- getting used to how suctioning feels when briefly off the ventilator

- techniques or a machine to help you cough more effectively
- using a nebuliser that delivers a fine mist of sterile salt water (saline) to loosen mucus.

Trache tube care: this usually means cleaning or replacing the inner cannula (the inner tubing) or changing the whole trache tube.

It also includes checking for signs of infection or irritation.

This happens while you're briefly off the ventilator, but your respiratory team will provide guidance and support.

Speech and swallowing support: if you find it harder to speak, swallow, eat or drink with trache ventilation, a speech and language therapist can help you with communication difficulties, safe swallowing and guidance on tube feeding.

A dietitian can make sure that you're getting the right nutrition.



For more information, see:

information sheet 7A – *Swallowing difficulties*

information sheet 7B – *Tube feeding*

information sheet 7C – *Speech and communication support*

4 How do I look after my ventilation equipment?

Your ventilator and any related equipment will need regular care and checks to keep it working properly and in case your needs change.

The organisation or service that supplied your equipment will also arrange regular servicing and support.

If you're unsure who to contact, ask your respiratory team.

Your respiratory team can also help with:

- training for you, your family or carers
- advice on cleaning and maintenance of equipment at home
- what to do if something stops working
- how to plan for possible emergencies.

If you're ever unsure about how to clean or replace something, ask your respiratory team or equipment provider.

Your team should also give you out-of-hours contact details for urgent help. Keep these in a safe and place, that's easy to access.

Non-invasive ventilation (NIV)

Regular maintenance might include:

- cleaning the mask
- replacing filters
- checking for worn out mask parts (like straps or cushions), which can cause air leaks.

Trache ventilation

Regular maintenance might include:

- having the entire trache tube replaced (usually by trained members of your care team)
- cleaning or replacing the inner cannula, which is a removable inner tube (carers or family members can be trained to do this)
- perform daily checks to prevent infection, blockages or skin irritation around the trache tube.

Your respiratory team can help you feel safe and supported when briefly off the ventilator for any checks or tube changes.

What if there's a power cut?

If you are fully dependent on your ventilator for more than 14 hours a day, it's essential to be prepared for power cuts.



“If you use a suction machine, a battery-operated machine is a must in case of power cuts.”

You or your carer need to:

- keep all batteries fully charged, for your ventilator and any related equipment, like suction pumps

- contact your energy supplier to place you under the Priority Services Register, which means you'll get advance warning of planned power cuts and faster support
- ask your energy supplier or care team if they can help you access a back-up generator for longer power cuts
- plan where you could go if the power is out for several days (whether you use ventilation part-time or full-time)
- have a spare ventilator and masks ready in case of any type of technical failure.



“We were on the energy supplier’s critical care list for urgent response in times of power cuts.”

How do I contact emergency services if I can’t speak?

If you have speech or communication difficulties and need urgent help, you or your carer can contact emergency services by text instead of calling.

Download the Relay UK app to your smartphone, tablet or PC, or make a call using a textphone.

For more on the service, see: www.relayuk.bt.com

What other equipment do I need to keep nearby?

Using either type of ventilation at home means you need to keep other equipment close to you at all times. For example:

- a suction machine
- a spare ventilator
- spare charged batteries
- a machine to help you cough, often called mechanical insufflation-exsufflation (MI-E)
- a humidifier
- extra tubing and other disposable parts (especially for trache ventilation).

The following section contains information about stopping ventilation and end-of-life. Read when you feel ready to do so.

5 What do I need to know about withdrawal of ventilation?

If you're using either NIV or trache ventilation, you have the legal right to stop at any time. This is known as withdrawal.

Choosing to stop ventilation is **not** the same as asking someone to help end your life (assisted suicide).

However, being dependent on ventilation means that you need this support to be able to breathe. This means choosing to stop is a refusal of life-sustaining treatment. This may be appropriate if:

- you feel that ventilation is no longer helpful or comfortable
- this type of support has become a burden to you
- your preferences for care have changed.

What happens if I stop using ventilation?

If you use ventilation part-time, you can simply choose not to put the machine back on. You will be supported as your breathing continues to weaken.

If you are fully dependent and cannot breathe without it, stopping ventilation is a more serious decision. This should be made with full understanding of what will happen next, as **it will cause a significant risk to your life**.

Withdrawal of ventilation when you are dependent, usually leads to death in a short amount of time. You'll be supported through this by your respiratory or palliative care team.

They will make sure:

- your symptoms are well managed, including medication to relieve breathlessness and anxiety
- your family or carers are supported before, during and after withdrawal.



For more on this process, see:
information sheet 8C – *Withdrawal of ventilation with MND*

Why do I need to plan ahead?

Thinking about future care with MND can be emotional and you may not feel ready yet. However, it helps if those close to you know your wishes for treatment and care, in case you become unable to make decisions.

Planning ahead with your family and care team can help you feel a sense of control. You may want to discuss:

- what is likely to happen in the later stages of MND and your choices about end-of-life care
- your thoughts on treatments that may extend life, including ventilation and tube feeding
- whether you would want to withdraw life-sustaining treatment in specific circumstances, such as ventilation
- what you would want to happen if you become too unwell to make decisions.

If these discussions feel upsetting, take each decision step by step. A trusted professional, such as a specialist in palliative care, can help you record guidance for others and facilitate family conversations about your wishes.

The sooner you can do this, the more time you have to make informed decisions and help your loved ones feel more prepared.

How can I record my wishes?

You can use various documents to guide others in your future care, but this guidance is only used if you become unable to make decisions for yourself. You can review or change any details at any time.

There are many ways to communicate your needs, wishes and preferences, but the following are often used to help plan ahead:

- **Advance care plan:** general guidance for others to follow when providing your future care.
- **Advanced decision to refuse treatment (ADRT):** when completed correctly, this legally binding document lets you refuse or withdraw treatments, including life-sustaining options such as ventilation
- **Power of attorney:** a legal arrangement where you appoint someone you trust to make decisions on your behalf. How this is done varies between nations in the UK.



For more about these options and other alerts, see:
information sheet 14A – *Advance Decision to Refuse Treatment
and advance care planning*

What if I choose to continue with ventilation?

You may wish to continue with ventilation, even if your care needs become complex. This is your right.

As your breathing continues to weaken, ventilation may no longer be effective. If you are unable to make decisions later on and your team believes ventilation is no longer helping or causing distress, they will use your recorded wishes to guide their decisions.

Your care team will always try to:

- act in your best interests and consult with those who know your preferences, such as members of your family, friends or carers
- ensure you are kept comfortable, whatever happens.

In most cases, end of life with ventilation is peaceful with the right care and support.



For more guidance, see:

- *End of life: a guide for people with motor neurone disease*
- information sheet 14A – *Advance Decision to Refuse Treatment (ADRT)
and advance care planning*

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

GOV.UK

Online government advice about support services, benefits and more.

Website: **www.gov.uk**

Health and Care Professions Council (HCPC)

Check their register to find qualified healthcare professionals.

Telephone: 0300 500 6184

Website: **www.hcpc-uk.org**

MND Scotland

Support for people affected by MND in Scotland.

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

myBreathing

Online resource about NIV with MND, with user videos.

Website: **<https://mybreathing.mymnd.org.uk>**

The National Institute for Health and Care Excellence (NICE)

See guideline NG42 for professional recommendations on MND care.

Telephone: 0300 323 0140

Email: nice@nice.org.uk

Website: **www.nice.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**

NI Direct

Government support and information for people living in Northern Ireland.

Email: through the website contact page

Website: **www.nidirect.gov.uk**

Relay UK

Text service for those with speech and communication difficulties.

Website: **www.relayuk.bt.com**

References

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,

Northampton NN3 6BJ

Acknowledgments

Thanks to our user reviewers for sharing their lived experiences with MND and carer support.

Thanks also to our expert panel for their reviews during the development and revision of this information sheet:

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Christina Faull, Palliative Medicine Consultant, LOROS, Leicester

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Martin Latham, Specialist Nurse, Sleep Service, St James Hospital, Leeds

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Dr Naveed Mustfa, Consultant Respiratory Medicine,
University Hospital of North Midlands

Jonathan Palmer, Nurse Consultant in Domiciliary Ventilation,
Plymouth Hospitals Trust

Our information resources

We have a range of accredited guidance, including the following information sheets.

1A – NICE guideline on motor neurone disease

3D – Hospice and palliative care

7A – Swallowing difficulties

7B – Tube feeding

7C – Speech and communication support

8A – Support for breathing problems

8C – Withdrawal of ventilation with MND

8D – Air travel and ventilation for motor neurone disease

10A-10G our range of guidance on financial support and social care

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

We also provide the following booklets and tools:

Living with motor neurone disease

Caring and MND: support for you

Caring and MND: quick guide

What you should expect from your care – to support conversations with your health and social care team

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

Getting around – travel, transport and holiday guidance

Understanding my needs – to guide others on your care needs.

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 if needed.

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 to 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:

Information feedback
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Francis Crick House
6 Summerhouse Road
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