



14A

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

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

With motor neurone disease (MND), you may want to plan and record your wishes for future care. This can help guide others if you become unable to make or communicate decisions for any reason. This information sheet explores approaches to advance care planning and how to make advance decisions to refuse or withdraw treatments, in set circumstances. The content includes:

1. What do the words mean?
2. How can I plan ahead?
3. How does an ADRT work?
4. How do I make and record decisions about ADRT?
5. What do I need to think about when refusing or withdrawing treatments?
6. How do I find out more?

Forms

Completed sample ADRT form

Blank ADRT form



Patient Information Forum

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



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



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

Find an example completed ADRT form to guide you at the end of this sheet, with a blank form to use if you wish. Download this sheet and an interactive ADRT form from our website, under Information sheets, at: www.mndassociation.org/careinfo

We offer support to people living with and affected by MND or Kennedy's disease in England, Wales and Northern Ireland. We try to ensure our information is accurate for all three countries, but always ask your GP or local health and social care providers how systems work in your area. In Scotland, contact MND Scotland for support.



See section 5: **How do I find out more?** for other organisations.

1. What do the words mean?

Mental capacity:

The ability to make or communicate a particular decision, usually about treatment or care.

Mental Capacity Act 2005:

An Act designed to protect and empower people in England and Wales who cannot make or communicate decisions, or need support to do so. This includes decision-making about finance, treatment or care.

Having mental capacity:

When a person is able to make or communicate a particular decision, even if they need support to do this.

Lacking mental capacity:

When a person is not able to make or communicate a particular decision, even with all possible support from the people supporting them.

Life-sustaining treatment:

A treatment that is helping to keep you alive.



Find more about mental capacity in our guide: **End of life care.**

The following content includes sensitive information about end of life decisions. Read when you feel ready to do so.

2. How can I plan ahead?

Discuss advance care planning with your GP, neurologist, specialist MND nurse or specialist palliative care team before making any decisions. They can advise you on:

- the options available to you
- the advantages and disadvantages of each option
- how to write your wishes correctly, so your guidance can be used if needed.



“It would have been helpful if someone had sat down with both of us and said, ‘these are the things you need to be thinking about’. It’s not pleasant having to think about and face these things, but it’s necessary.”

Why do I need to think about planning ahead?

Thinking about the future with MND can be emotional, both for yourself and those close to you. Planning ahead often leads to sensitive discussions about end of life decisions and you may not feel ready. However, making decisions and providing guidance about your future care can help ease anxiety.



“I had put it off for so long that it was a weight off my shoulders. It helped me address a number of issues which were on my mind... and to set them aside.”

Recording clear written instructions about your wishes can assist others, in case you become unable to make or communicate decisions (even with support). This is known as lacking mental capacity.

Have conversations about your wishes as early as you can, as MND can affect the following.

Energy levels

MND can cause extreme tiredness (known as fatigue), which makes it harder to manage complex conversations.

Speech and communication

If speech, gesture and expression are affected, conversations become harder and more tiring. These symptoms get worse over time.

Thinking and behaviour

Up to half of people with MND experience some changes to thinking and behaviour. This number increases in the later stages. Although these changes are usually mild, they can be more severe, making it harder to process information.

If you lose capacity to make particular complex or difficult decisions, you still have the right to make other choices, such as what you want to do during the day. Other people will only make a decision on your behalf if you have lost mental capacity, after having all possible support to make or communicate each decision.

Who can help me start to think about my decisions?

If you feel overwhelmed about making decisions, ask your health and social care team to help you work through the options available. For example, ask them how to record your decisions in an appropriate way to guide others about your future care.



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

Don't be afraid to raise the subject yourself. Many professionals find it difficult to know if you are ready for these conversations. To open a discussion, try something like: 'I'm worried about the future and wondered if you could help me plan ahead for my care?'

What is a doula?

You may find it useful to chat to a doula, especially if you don't have a close family network. Doula is the name for a health professional who specialises in helping people through a major event in their lives.

This includes trained end of life doulas, for support with planning ahead or to explore feelings and wishes. Ask your health and social care team if this is something you want to know more about. You can also contact our MND Connect helpline for practical guidance and how to find emotional support services.



“I am personal and my care should be personal...one size does not fit all.”

What are the different ways I can plan ahead?

You can approach future care using various resources for planning.

Advance care plan

Discuss your preferences for future care with your health and social care team and those close to you. From these discussions, your professionals can help you create a written Advance Care Plan (ACP). This sets out your preferences for future care. Although not legally binding, your ACP guides others in your care if you become unable to make or communicate decisions. This might include:

- special requirements for food and drink
- how any spiritual and religious beliefs should be reflected in your care
- who you prefer to provide personal care and how this should be delivered
- your preferred location for care and preferred place of death
- arrangements for dependants, particularly if they need care arranged
- how to manage practical issues, such as emergency care for your pet.



See the end of this section for details of the ReSPECT form, which you can use to record preferences for treatment and care in case of emergency situations.

Advance statement

You can write down an advance statement about your wishes, feelings, values and preferences, about what you do or don't want to happen with your future care and treatment. This can be written separately or included with advance care planning documents. The statement can then be used to guide others making decisions on your behalf, if you lose mental capacity, but advance statements are not legally binding.

Advance Decision to Refuse Treatment (ADRT)

You can write down instructions in an ADRT to refuse or withdraw specific treatments in the future if you become unable to make or communicate decisions (lacking mental capacity). However, you cannot ask for new treatments to be introduced in an ADRT.

An ADRT will be legally binding in England and Wales if:

- it is completed correctly
- all the conditions stated in the ADRT are met
- you can no longer make or communicate decisions about treatments in your ADRT.

An ADRT is not legally binding in Northern Ireland, but it can still help guide your health professionals.



See sections 3 and 4 in this sheet for details about creating and using an ADRT.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

When your heart and breathing stop (known as cardiopulmonary arrest), healthcare professionals may try to restart them (cardiopulmonary resuscitation, or CPR). A DNACPR is a written instruction to **not** try to restart the heart and breathing.

This can be made and recorded in advance to guide healthcare professionals if a person's heart and breathing stop. This decision should be made in discussion with you, or someone close to you, if you lose capacity to make this decision. This conversation may be raised by a healthcare team.



See section 5: **What do I need to think about when refusing or withdrawing treatments?** for more on resuscitation.

Other ways to plan

You can plan ahead in other ways, such as making a will to decide what happens with your money and belongings (known as your estate) after your death.



When you feel ready to tackle wider end of life decisions, see our guide: **End of life care**, which includes how to put your affairs in order.



"It's positive to do the practical things, eg making a will. That's something you can do and tick off the list...it makes me feel in control."

How do I give someone power of attorney?

With power of attorney, you legally grant authority to one or more people (known as attorneys) to make decisions on your behalf. This could be a family member, friend, partner or civil partner, or professional (such as a solicitor). You must grant power of attorney while you have mental capacity.

Find and complete forms to grant power of attorney online, as shown in the following headings. These can take time to complete and the law governing power of attorney is complex. Qualified legal advice is recommended on the creation, registration, and use of powers of attorney. This will include safeguards for you and the person you appoint.

There will be a charge for legal help, in addition to the registration fee for your power of attorney, so ask about the costs before you begin. You may qualify for some fee exemptions if you live in England or Wales.

In England and Wales

In England or Wales, you can apply for Lasting Power of Attorney (LPA), which requires a legal document to be registered with the Office of the Public Guardian (OPG). You will be charged a registration fee. See: gov.uk/power-of-attorney

An LPA can be used to manage either one or both of the following:

- property and finance decisions (with your agreement, this can be used by the appointed person to support you, even if you can still make decisions yourself)
- health and personal welfare decisions (only used if you can no longer decide or communicate for yourself). These can include specific instructions on life-sustaining treatment.

If an LPA only covers property and finance, any previous ADRT remains valid. But if you include decision-making about life-sustaining treatments in your health and welfare LPA, this will invalidate your ADRT if you made one previously.

Your ADRT would still act as a guide, but the person appointed as your attorney in the LPA will have the higher authority. This means they could make decisions that may be different to those in your ADRT. However, if you make a new ADRT or revise your existing one after the LPA is made, it will not be invalidated. This means that your attorney must follow what your new ADRT directs.

If created in England or Wales before 2007, power of attorney was called an Enduring Power of Attorney (EPA). An EPA can only be used for property and finance decisions.

In Northern Ireland

Enduring Power of Attorney (EPA) is used in Northern Ireland and registered through the Office of Care and Protection. An EPA only enables decisions on your behalf concerning property and finance, not personal welfare or care-related matters. You cannot use an LPA in Northern Ireland. For more guidance, see: nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney



See our guide: **End of Life care** for more about power of attorney and other advance planning.

How do I prepare for urgent situations?

You may need urgent medical or social care at some point. Think about the following questions to help you plan:

- What will happen if my main carer is unable to support me for any reason?
- Where can I find appropriate respite care or support if my carer needs a break?
- How can we access emergency treatment out of clinic or GP surgery hours?

Keep contact details for emergency care teams, along with care notes and advance care documents, where they can be easily found if needed.

Ask the following teams for guidance:

- your GP and wider health and social care team, who can advise on local support systems and refer you to specialist help
- specialist palliative care professionals, for indepth guidance on symptom control and end of life care (ask your GP or another healthcare professional to refer you)
- adult social care services for assessment of your care needs.

You and your carer both have the right to an assessment of your needs, either together or as individuals. A needs assessment for yourself or a carer's assessment if you're a carer, is usually done by a social worker or key worker.

It gives each of you the opportunity to find out about available support for urgent situations or emergencies. They can also advise and arrange care services to help with daily activities.

Contact adult social care services through your local authority or council in England, Wales or Scotland, or your local health and social care trust in Northern Ireland.



See information sheet: **3D Hospice and palliative care** and our booklet: **Types of care** for more about palliative care professionals. See also information sheet: **10B What is social care?**

If you create an advance care plan or an ADRT, keep these documents secure but easy to find and access in an emergency.

Locking them away could make it difficult to access them when needed. Paramedics and medical teams need to see these to be able to carry out your wishes.

Let your carers know where you keep these too.

You may also find the following useful to help you prepare for urgent situations:

Message in a bottle

A sticker on your fridge and the inside of your front door tells paramedics or other healthcare professionals that medical details can be found inside your fridge. These details are in a special bottle they will recognise.

You can add a note inside to explain where you keep documents such as your Advance Care Plan or ADRT.

These bottles are free from your local chemist or find details through the Lions Clubs website: lionsclubs.co.uk

Carer's Emergency Card

This can be carried by a carer to alert someone that you receive and need care, in case your carer is involved in an accident and unable to support you.

The cards are usually available from your local authority, who may also have a registration service to direct services to you, should an emergency arise.

MedicAlert

This registered charity offers an identification system for people with medical conditions and allergies. This is usually provided in the form of a bracelet or necklet, which you pay for. See: medicalert.org.uk for details, including their 24-hour emergency telephone service.

Their bracelet or necklet can include an engraving of the words: advance decision. This alerts healthcare professionals that you have an ADRT. They also create an electronic medical record for you and you can include a copy of your ADRT.

Digital Alerts

You can download apps to your phone in case of emergency situations. These apps allow someone to see vital health information written on the locked front screen of your phone.

This information could include an ICE (in case of emergency) contact. You can also show alerts, such as whether you're at risk with oxygen.

As long as your phone remains functional, emergency responders can see this key information, even if you're unconscious.

Look in your phone app store and search for: Medical ID:ICE

At the MND Association, we also provide the following to help in urgent situations:

MND Alert Card

Keep this small card in your purse, wallet or pocket, to alert hospital staff that you have MND if admitted. It lets them know you need specialist help, with space for you to write key contacts. The card also warns that you may be at risk with oxygen.

MND Alert Wristband

You can wear this wristband at all times, if wished, to alert medical teams that you have MND. The band also warns that you may be at risk with oxygen, with a web address for professionals to read about urgent and emergency support for MND.

Understanding my needs

Use this form to record basic notes about your needs. It lets you explain how you would like to be cared for if admitted to hospital or a hospice. Designed with MND in mind, it can also be used to explain your needs to care workers and care services.

How do I share my decisions with professionals?

There are various ways for local healthcare systems to share your medical records, including advance care plans and ADRTs. This helps healthcare professionals know your needs, wishes and preferences. Ask your GP about local systems, as these can vary. For example, some ambulance services may keep a copy of your ADRT, depending on your circumstances. Ask your healthcare team about the following:

Summary Care Record

An electronic record of your basic health information, which can be seen by healthcare professionals involved in your care. You can add more information to your Summary Care Record, such as your preferences for future care and advance care planning documents. Anyone registered with a GP in England has a basic Summary Care Record, unless they specifically choose not to have one.

Electronic Palliative Care Co-ordination Systems (EPaCCS)

These systems exist in some areas to enable end of life and palliative care records to be shared with different professionals.

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

ReSPECT helps you and your healthcare professionals agree recommendations for your care in emergency situations. If you cannot make or communicate decisions, the resulting ReSPECT form is easy for healthcare teams to use and access. It combines wishes for your future care, including clinical recommendations, with your preferences about Cardiopulmonary Resuscitation (CPR). ReSPECT is being adopted across the UK. You can find out more at resus.org.uk/respect

3. How does an ADRT work?

If you are aged 18 or more, you can use a form called an Advance Decision to Refuse Treatment (ADRT) to guide professionals in decisions about medical treatments.

This form enables you to refuse or withdraw specific treatments, in specific circumstances in the future. This can include life-sustaining treatments, such as assisted ventilation or tube feeding. You can verbally refuse or withdraw treatment at any time. However, if you become unable to make or communicate decisions, your instructions need to be in writing, in a valid ADRT.

ADRTs are governed by the Mental Capacity Act 2005 in England and Wales. An ADRT will be a legally binding document if it is valid and applies to the decision being made.

You must have mental capacity to make and communicate your own decisions when you make your ADRT. You can ask a trusted person to help you write your ADRT instructions if needed.

Your ADRT can only be used if you become unable to make or communicate your advance decisions. All efforts should have been made to help you communicate.

An ADRT is sometimes known as an Advance directive, or a Living will, but the Mental Capacity Act 2005 does not use these terms and they have no legal meaning.



“By making an ADRT I’m hoping it will psychologically help my partner to make these difficult decisions by saying ‘this is ok, this is what I want’.”

Will an ADRT apply in Northern Ireland?

The Mental Capacity Act 2005 does not apply in Northern Ireland, which means an ADRT is not legally binding there. However, it can still be used by health and social care professionals to help guide their decisions, based on your preferences.

Do I have to make an ADRT?

No. Whether or not to make an ADRT is your choice. This might depend on your outlook, faith or how discussions with family and professionals inform your views.

If you do make an ADRT, and include decisions about life-sustaining treatments, it must be completed correctly, and signed and witnessed to be legally binding.



See section 4: **How do I make and record decisions in an ADRT?**

Making an ADRT can bring a sense of personal control, but:

- you need to give precise statements about what you want to happen and in what circumstances
- everyone involved in your care needs to be aware of your ADRT
- you can still discuss your wishes for future care with your healthcare team, even without an ADRT
- you can write your preferences in another advance care planning document, but these records won't be legally binding like an ADRT
- anyone involved in your care can still use other instructions to inform decisions they may need make on your behalf.

Who needs to know about my ADRT?

People can only act on your wishes if they know about them. That means everyone involved in your care needs a copy of your ADRT, including:

- your carer, partner, and close relatives or friends
- your GP and key members of your health and social care team
- local paramedics and emergency teams
- the person you have appointed as attorney, if you have Lasting Power of Attorney or Enduring Power of Attorney in place.



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

Keep a list of everyone who has a copy, but your original signed ADRT should be easy to access. In urgent situations, healthcare professionals may need to see the original to act upon your wishes.

In urgent or emergency situations, medical staff may not know you. For this reason, you may want to use alerts to inform others that you have an ADRT.



See section 2: **How can I plan ahead?** and the heading: **How do I prepare for urgent situations**, for more about alert resources.

What happens if I change my mind or need to amend my ADRT?

If you make different decisions, or your views change before your advance decisions may be needed, update your ADRT form.

For example, it could be confusing if your ADRT says you do not want assistive ventilation introduced under any circumstances, but you start using ventilation in the meantime.

You can change your mind about anything in your ADRT at any time. As your views, circumstances, illness and treatment may change, it is useful to review your ADRT on a regular basis.

If you do make changes, inform everyone that has a copy, give them a new copy and ask them to destroy the previous one.

It is important to notify your attorney for your Lasting Power of Attorney (LPA) if you have one. An ADRT dated more recently than an LPA cannot be overruled by the LPA for decision-making on life-sustaining treatment.



See section 2: **How can I plan ahead?** and the heading: **How do I give someone power of attorney?**

Even if you do not make changes during a review, add a date and signature to your ADRT to show it's up to date. This shows when you made your most recent decisions. Again, this will affect your Lasting Power of Attorney if you have one.

4. How do I make and record decisions in an ADRT?

Before making your ADRT, ask your healthcare team for guidance to ensure:

- you are clear about which treatments you wish to refuse or have withdrawn
- you understand what might happen, such as putting your life at risk
- you complete the ADRT form correctly (you need to be 18 years old or more).

An ADRT is a legal document governed by the Mental Capacity Act 2005 and will not be legally binding unless it is completed correctly. Using the blank ADRT form at the end of this sheet, or a blank form provided by another reputable organisation, can help you ensure your ADRT meets all requirements.

An ADRT can be recorded in verbal or written format, but if it includes decisions about life-sustaining treatment, it must be written (handwritten or typed). You can ask someone to help you complete the form if needed.

What details *must* be included in an ADRT?

As well as your personal details, you must include the following for your ADRT to be legally binding:

- the specific treatments you want to refuse or have withdrawn
- the circumstances in which you want this to happen (you can refuse a treatment in all circumstances if you wish).

If you include decisions about life-sustaining treatment, it must be written, witnessed and include the following:

- your signature or the signature of another person on your behalf, carried out in your presence and under your direction
- a declaration that your decisions apply, **'even if my life is at risk as a result'** (the phrase in bold must be used).

What details are useful to include in an ADRT form?

It helps to include the following in a written ADRT:

- the name and address of your GP
- the dated signature of at least one witness over the age of 18 (ideally not a partner, spouse, relative, anyone with power of attorney or who could benefit in your will)
- the name, address and telephone number of any person you have nominated to be consulted about your wishes
- names of those with copies (such as your doctor, family or ambulance service).

We have given space for these details in the blank ADRT form at the end of this sheet, along with a sample completed ADRT form.

What decisions can be included in an ADRT?

You can refuse the introduction of treatment that may be life-sustaining. You can also ask for a treatment to be withdrawn, in precise circumstances, if it is no longer helping or has become a burden.

For example, your ADRT may include decisions about refusal or withdrawal of:

- mechanical breathing support (non-invasive or invasive ventilation)
- tube feeding
- antibiotics.

You can also include a statement that you do not want resuscitation to be attempted in an emergency.

Have a discussion with your healthcare team about:

- possible treatment decisions you may need to make in the future
- when each treatment may be offered
- the benefits and burdens of these treatments
- how the treatment may be stopped and symptoms managed in another way
- what will happen if the treatment is refused or withdrawn.

What decisions cannot be included in an ADRT?

An ADRT cannot be used to:

- decline basic nursing care needed to keep you comfortable
- ask for anything, such as medication, to deliberately cause or speed up death
- ask for new treatments to be introduced
- determine what should happen following your death (an ADRT is not a will)
- donate your body to medical research.

You can include further information in your ADRT about your general preferences for care, but this will only guide professionals, as they will not be legally binding in the same way as an instruction to refuse or withdraw treatment.

It is usually more effective to use an Advance Care Plan for general care preferences.

The following section contains sensitive information about what will happen when refusing or withdrawing specific treatments. Read when you feel ready.

Where can I get an ADRT form?

At the end of this information sheet you will find an example of a completed ADRT form to help guide you and a blank form to use if you wish.

You can also download this form to complete on a computer, tablet or mobile device and print off. Find this information sheet and the form on our website by selecting: Information sheets, at: mndassociation.org/careinfo

You can also ask a healthcare professional, such as your GP or a member of your hospital team, for a form. They can also provide guidance on advance decisions.

Ask your GP or specialist palliative care team if you need to use standard forms for advance care planning in your area. Using preferred documents help professionals feel confident about its use. This also helps paramedics and emergency care teams, as they are usually working under pressure.

5. What do I need to think about when refusing or withdrawing treatments?

You may receive the following treatments with MND, which can be refused or withdrawn, if wished. If you have other health conditions, as well as MND, there may be other things you need to think about.



“From our experience, it is better to be in a position where you feel as prepared as you can be.”

Assisted ventilation

What is it?

Assisted ventilation is where a machine helps support your breathing. There are two types of assisted ventilation:

- Non-invasive ventilation (NIV) provides extra air flow through a mask
- Trache ventilation (tracheostomy or invasive ventilation) supports breathing through a tube inserted into the windpipe, through the neck.

Over time, you are likely to become dependent on either type of ventilation with MND. This means it becomes a life-sustaining treatment.



See information sheets: **8A-8D** for breathing support, including withdrawal of ventilation.

What do I need to think about when refusing ventilation?

Refusing either type of ventilation in your ADRT means you don't want it provided in the future. Breathing problems do get worse as MND progresses, so your life will be at risk without ventilation.

However, your respiratory team will advise on positioning, medication and other support to ease anxiety and breathlessness.

What do I need to think about when having ventilation withdrawn?

If you use ventilation to support your breathing, there may come a time when you feel it no longer helps or has become a burden.

It is your right to ask for it to be withdrawn at any time, or at a specified point in the future, even though your life will be at risk. You need to provide clear details in your ADRT about the circumstances in which you would want this to happen.

If you are dependent on either type of ventilation when it is withdrawn, death is likely to follow in a relatively short period of time. This is usually peaceful, and medication can be provided to relieve feelings of breathlessness and anxiety.

Trache ventilation may prolong your life, but symptoms will progress. This impacts on future care, as you will need increasing support.

It is possible to use trache ventilation at home, but you may need 24-hour care in a hospital or nursing home.

Trache ventilation can be introduced during emergency treatment, especially if resuscitation is attempted. Once recovered, trache ventilation is usually withdrawn for most people, but can be difficult to stop using with MND, as breathing can weaken.

If you decide you do not want assisted ventilation introduced, even in an emergency, you need to be specific about this in your ADRT.

Tube feeding

What is it?

You can receive food, drink and medicine through a feeding tube inserted into your stomach through the abdominal wall. This is fitted with a small operation in hospital.

You can use the feeding tube to top up meals at first. This means you can still eat and drink by mouth, for as long as you feel safe or wish to do so.

However, if you reach a point where tube feeding is the only way that you can receive food and drink, it will become a life-sustaining treatment.



See information sheets: **7A Swallowing difficulties** and **7B Tube feeding**, and our guide: **Eating and drinking**.

What do I need to think about when refusing a feeding tube?

If your swallowing ability weakens with MND, this will progress. Over time, this means your life may be at risk without tube feeding.

Your dietitian and speech and language therapist will continue to advise on nutrition and fluids, with or without a tube fitted.

If you do not want to have a tube fitted in the future, you need to be exact in your ADRT about the circumstances in which you would refuse this.

Swallowing problems can cause bits of food and drink to get into the lungs (known as aspiration). This can cause chest infections, which may develop into aspiration pneumonia. Tube feeding reduces the risk of aspiration and related chest infections.



“We had several visits that helped us think over challenges we were going to face. And by discussing tube feeding, it made me realise it was going into hospital I feared the most, not the procedure.”

What do I need to think about when having a feeding tube withdrawn?

If you use a feeding tube, there may come a time when you feel it will no longer help or may become a burden.

It is your right to ask for it to be withdrawn at any point, but also in advance. You can state in your ADRT when to stop your tube feeding in the future, even though your life will be at risk.

In most cases with withdrawal, the tube is not used, rather than having it taken out.

When eating and drinking by mouth are no longer possible, or you have the feeding tube withdrawn, you may not feel as hungry as you might fear. This is because your appetite is likely to decrease throughout the course of the disease.

You can stop receiving food, drink, medicine or all of these through your tube. Without another way of receiving nutrition or fluids, your life will be at risk.

If you are relying on tube feeding and stop using it, a natural death will follow over a period of time. The speed at which this happens varies from person to person.

However, your healthcare professionals can help you feel more comfortable. You can also continue to receive medicine through your tube, even if you decide to stop having food or fluids in this way.

Antibiotics

What are they?

Antibiotics are a type of medicine used to treat infections.

What do I need to think about when refusing antibiotics?

If you refuse antibiotics, the infection they treat may not get better. There may be a risk to your life if the infection is life-threatening.

Be specific about the circumstances in which you want to refuse antibiotics in your ADRT. For example, you may wish to refuse antibiotics that treat an infection that could be linked to the progress of MND, like aspiration pneumonia.

However, you may still want antibiotics to be used to treat an infection not directly linked to MND, such as a water infection (urine infection).

You can also decide whether to refuse antibiotics given to you in a certain way but not others. For example, you may wish to continue receiving antibiotics through a feeding tube, but not into your veins (intravenously).

If you do choose to refuse antibiotics in your ADRT, you can still expect your health and social care team to provide the best possible support. This would include managing any distressing symptoms and helping to keep you comfortable.

Cardiopulmonary resuscitation (CPR)

What is cardiopulmonary resuscitation?

Cardiopulmonary resuscitation is often shortened to (CPR). It is the process of trying to restart a person's heart and breathing if they have stopped (this is called cardiopulmonary arrest).

You can choose whether you want to refuse resuscitation completely or under certain circumstances in the future. A recorded decision to refuse resuscitation is often called a DNACPR (Do not attempt cardiopulmonary resuscitation).

A DNACPR should be made and signed by your healthcare team, in discussion with you, or someone close to you if you don't have mental capacity to make this decision.

It can guide healthcare professionals who are present if your heart and breathing stop. You can choose to refuse resuscitation in advance in an ADRT, which will be legally binding in England and Wales.

Without a DNACPR, healthcare professionals will attempt CPR in most cases, especially if they are unfamiliar with your medical history. However, there may be a reason why CPR is unlikely to work as MND progresses. In this case, CPR may not be attempted.

What do I need to think about when refusing an attempt at resuscitation?

If you choose to refuse an attempt at resuscitation in the future, and your heart and breathing stop at any point, you need to be aware that death will follow.

You must be clear and specific in your ADRT about the circumstances in which your refusal of resuscitation will apply, as your healthcare team may need to make quick decisions in unexpected situations.

For example, you may not wish to be resuscitated if something related to MND causes your heart or breathing to stop working.

However, you may feel differently about resuscitation at an earlier stage of the disease (as in the event of an accident).

If you have a DNACPR, you can still expect to receive the best possible medical and nursing care to ensure your comfort.

It may help to be aware of the following:

- a DNACPR is sometimes known as a DNAR (do not attempt resuscitation) or DNR (do not resuscitate)
- the decision to attempt CPR is made by the clinical team in charge of your care
- neither you nor your family can insist that CPR be tried
- a DNACPR can be suspended or cancelled as circumstances change.

For example, it could be suspended if you need surgery, as CPR may be appropriate in the unlikely event that it's needed during that short time.



“We've agreed not to have any resuscitation, but we did ask for full escalation for any infections. So if Mum picks up a chest infection, we still want treatment. The reason we've decided for that is because Mum has grandchildren... they come with coughs and colds, so we were just worried that if we can just try and treat Mum's infection with some antibiotics or treatment other than CPR, then yeah, great...”

6. How do I find out more?

Other organisations

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

The Cinnamon Trust

Help for people who are older or with a life-shortening illness to care for their pets.

Tel: 01736 77 900
Email: through the website contact page
Website: cinnamon.org.uk

Citizens Advice

Free, confidential advice to help resolve legal, money and other problems.

Tel: 0800 144 8848 (England)
0344 477 2020 (Wales)
Website: citizensadvice.org.uk (England)
citizensadvice.org.uk/wales (Wales)
citizensadvice.org.uk/nireland (Northern Ireland)

Dying Matters

Ways to help people start conversations about dying, death and bereavement.

Website: hospiceuk.org/our-campaigns/dying-matters

Government information

Online government information about benefits and support.

Website: gov.uk (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

Hospice UK

For information about hospice care and help finding your nearest hospice.

Tel: 020 7520 8200
Email: info@hospiceuk.org
Website: hospiceuk.org

Lions Clubs International (British Isles and Ireland)

A community organisation, with guidance about the Message in a Bottle scheme.

Tel: 0845 833 9502
Email: enquiries@lionsclubs.co.uk
Website: lionsclubs.co.uk

MedicAlert

An alert system for medical conditions and allergies, with a 24-hour telephone service.

Website: medicalert.org.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: mndscotland.org.uk

NHS and UK healthcare

Information and urgent support from NHS services and healthcare in the UK.

Tel: 111 (England, Wales and Scotland)
for Northern Ireland, see individual trust contact page
Website: 111.nhs.uk (For England)
111.wales.nhs.uk (For Wales)
hscni.net (For Northern Ireland)
nhs24.scot (For Scotland)

The Office of Care and Protection

Handles applications for Enduring Power of Attorney (EPA) in Northern Ireland.

Tel: 028 9072 5953
Website: search for *enduring power of attorney* at: nidirect.gov.uk

Office of the Public Guardian

Handles applications for Lasting Power of Attorney (LPA) in England and Wales.

Tel: 0300 456 0300
Email: customerservices@publicguardian.gov.uk
Website: gov.uk/government/organisations/office-of-the-public-guardian

The Patient Advice and Liaison Service (PALS)

Confidential help in England about NHS services and complaints.

Website: [nhs.uk/nhs-services/hospitals/
what-is-pals-patient-advice-and-liaison-service](http://nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service)

Patient and Client Council - Northern Ireland

An independent voice for patients, carers, and communities in Northern Ireland

Tel: 0800 917 0222
Email: info@pcc-ni.net
Website: pcc-ni.net

ReSPECT

An NHS process to record your preferences and decisions for emergency care.

Email: through the website contact page
Website: resus.org.uk/respect

Samaritans

Confidential emotional support, 24 hours a day.

Email: jo@samaritans.org
Website: samaritans.org

Acknowledgements

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

Thank you also to the following for their kind review during the development or revision of this information sheet.

Simon Chapman	Formerly Director of Policy and External Affairs at NCPC and Dying Matters, now consulting via @SimonSimply
Idris Baker	Consultant in Palliative Medicine, ABM University Health Board, South Wales.
Christina Faulf	Palliative Medicine Consultant, LOROS, Leicester.
Emma Husbands	Palliative Medicine Consultant, Gloucestershire Royal Hospitals NHS Trust.
Heidi Jew	Care Centre Coordinator, Birmingham MND Care Centre.
Ben Lobo	National Lead for ADRT Project Team, Mid Trent Cancer Network.
David Oliver	Consultant in Palliative Medicine, Wisdom Hospice, Rochester and Honorary Reader, Centre for Professional Practice, University of Kent.
Catherine Whitaker TEP	Solicitor and Director of Legacy Law Limited, Wokingham.

References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

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

Further information

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

Information sheets

- 1A NICE guideline on motor neurone disease
- 3D Hospice and palliative care
- 7A Swallowing difficulties
- 7B Tube feeding
- 7C Speech and communication support
- 8A Support for breathing problems
- 8B Ventilation for motor neurone disease
- 8C Withdrawal of ventilation
- 8D Air travel and ventilation
- 10A to 10G Our range of sheets on benefits, social care and wider support

Booklets

- Changes to thinking and behaviour
- Emotional and psychological support
- Telling people about MND
- What you should expect from your care
- Caring and MND - quick guide

Large guides

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

Other resources

- Understanding My Needs
- MND Alert Card
- MND Alert Wristband
- The Mental Capacity Act 2005: legislation.gov.uk/ukpga/2005/9/contents

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

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

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

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

Our support

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

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: mndassociation.org/mndconnect

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

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

Local and regional support

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

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: mndassociation.org/benefitsadvice or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: mndassociation.org

Online forum: forum.mndassociation.org

We welcome your views

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

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

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

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

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

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

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

Example copy for reference only

My Advance Decision to Refuse Treatment (ADRT)

1. My details

My personal information –	
Name: Sample text: Mr A Smith	Any distinguishing features in the event of unconsciousness: Sample text: Mole on chin
Address: Sample text: 1 The Avenue Anytown AA1 1ZZ	Date of birth: Sample text: 01 January 1958
	National Health Service (NHS) number: Sample text: 000 000 0000
	Telephone number: Sample text: 1234 123 123

What is this document for?

This document has been completed by me or with my authorisation. It states in advance any treatments I do not want in the future, under specific circumstances. This form replaces any previous ADRT that I have made.

It should only be used if I can no longer refuse or consent to treatment because I have become unable to make or communicate (by any means of communication) decisions about my healthcare.

By completing this document, I understand it is still my right to receive basic care, support and comfort.

Advice to anyone reading my ADRT:

Before any actions are taken, please do not assume I have lost capacity to make decisions about my medical treatment or to communicate them. I may need help and time to make and communicate decisions. I may have to use an alternative method of communication, which may include a communication aid.

If I have lost capacity to make decisions about my medical treatment, please check the validity and applicability of this ADRT. If it is valid and applicable, please ensure that you act on it, as it is a legal document.

Please help to share this information with relevant colleagues involved in my treatment and care, who need to know about this. Please also check if I have made any other statements about my preferences or wishes that might be relevant to my advance decisions.

Example copy for reference only

2. My condition

In relation to my health problems, I have been diagnosed with the following –

Sample text:

Motor neurone disease (MND), a life-shortening condition that progressively affects my muscles and has no cure.

This affects me in the following ways –

Sample text:

I am becoming progressively weaker. This condition causes great problems with daily activities including eating and drinking.

I have talked about my feelings with my family. This is the right time for me to make my advance decisions about my future care and treatment, as I am having increasing difficulties with speech and communication.

I know MND will shorten my life and I wish to make choices about what will happen with my future care and treatment at end of life.

My advance decisions in this ADRT state any treatments I wish to refuse or withdraw if they are no longer working and have become a burden, even if this means my life is at risk.

Example copy for reference only

3. My advance decisions

The following instructions state which treatments I wish to refuse and the precise circumstances in which each action will apply.

Please note, these are examples only and your advance decisions or circumstances in which you want these to apply may be different. Discuss your wishes and needs with your health and social care team before making these decisions.

<p>Unless stated otherwise below, I confirm that the following decisions to refuse treatment are to apply even if my life is at risk as a result.</p> <p>Please tick this box if you agree with this statement: <input checked="" type="checkbox"/></p>	
I wish to refuse the following specific treatments –	In these circumstances –
<p>Sample text: Cardiopulmonary resuscitation (re-starting your heart and breathing)</p>	<p>Sample text: I wish to refuse cardiopulmonary resuscitation in the event that I have a cardiac or respiratory arrest due to the impact of motor neurone disease or any related condition, such as a severe chest infection.</p>
<p>Sample text: Non-invasive ventilation (where a machine helps to support your own breathing through a mask)</p>	<p>Sample text: I wish to have non-invasive ventilation withdrawn if despite simple attempts to position me, clear my airway and remove secretions, I can no longer breathe by myself without the help of the machine.</p>
<p>Sample text: Invasive ventilation (where a machine breathes for you following a tracheostomy)</p>	<p>Sample text: I wish to refuse invasive ventilation if I cannot be consulted about its use during emergency treatment or resuscitation.</p>
<p>Sample text: Alternative feeding methods (through a tube into your stomach or by drip)</p>	<p>Sample text: I wish to stop receiving food and fluids through my feeding tube when I can no longer swallow safely, even with the help of others.</p>

<p>Unless stated otherwise below, I confirm that the following decisions to refuse treatment are to apply even if my life is at risk as a result.</p> <p>Please tick this box if you agree with this statement: <input checked="" type="checkbox"/></p>	
<p>Sample text: Antibiotics</p>	<p>Sample text: I wish to refuse antibiotics in the event that I have a severe chest infection that may threaten my life.</p>

Example copy for reference only

4. My signature

<p>My signature (or nominated person):</p>	<p>Date of signature:</p> <p>This should be the same date as the witness signatures as they are witnessing your signing of the form.</p>
---------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------

Example copy for reference only

5. Witness signatures

<p>Witness statement:</p> <p>I testify that the maker of this Advance Decision to Refuse Treatment signed it in my presence and made it clear that they understood what it meant. I do not know of any pressure being brought on this person to make such an advance decision and I believe it was made by their own wish. As far as I am aware, I do not stand to gain from this person's death.</p>	
<p>First witness –</p>	
<p>Name:</p>	<p>Address:</p>
<p>Signature:</p>	
<p>Date signed:</p> <p>They are witnessing your signature, so this should be the date when you sign the document.</p>	<p>Telephone number:</p>

Second witness – (only one witness is required, but it is preferable to have two)	
Name:	Address:
Signature:	
Date signed:	Telephone number:

Example copy for reference only

6. Important contacts

If you need to discuss my wishes, the person I would like you to contact first is -	
Name: Sample text: Mrs A Smith	Relationship: Sample text: Wife
Address: Sample text: 1 The Avenue Anytown AA1 1ZZ	Telephone: Sample text: 01234 123 123
I give permission for this document to be discussed with my relatives/carers: (please tick this box if you agree with this statement): <input checked="" type="checkbox"/>	
I have discussed this document with the following health and social care professional –	
Name: Sample text: Dr Jones	Profession/job title: Sample text: Neurologist
Contact details: Sample text: Neurology Ward Anytown Hospital Anytown AA1 1DE	Date document was discussed: Sample text: 1 February 2026

My General Practitioner (GP) is –	
Name: Sample text: Dr Blake	Telephone number: Sample text: 02345 234 234
Address:	

Example copy for reference only

8. Further information

The following information is important to me, but does not directly relate to my Advance Decision to Refuse Treatment –
<p>Sample text:</p> <p>If this ADRT becomes valid because I can no longer make decisions or communicate, I would prefer to:</p> <ul style="list-style-type: none"> – stay at home if possible – have my family around me – continue to have medication for symptom control and comfort



This is the end of the example form. See the following pages for a blank form to create your own ADRT, if you wish.

Download this form to complete it on screen, by selecting this sheet, under: information sheets, at: www.mndassociation.org/careinfo

My Advance Decision to Refuse Treatment (ADRT)

1. My details

My personal information –	
Name:	Any distinguishing features in the event of unconsciousness:
Address:	Date of birth:
	National Health Service (NHS) number:
	Telephone number:

What is this document for?

This document has been completed by me or with my authorisation. It states in advance any treatments I do not want in the future, under specific circumstances. This form replaces any previous ADRT that I have made.

It should only be used if I can no longer refuse or consent to treatment because I have become unable to make or communicate (by any means of communication) decisions about my healthcare.

By completing this document, I understand it is still my right to receive basic care, support and comfort.

Advice to anyone reading my ADRT:

Before any actions are taken, please do not assume I have lost capacity to make decisions about my medical treatment or to communicate them. I may need help and time to make and communicate decisions. I may have to use an alternative method of communication, which may include a communication aid.

If I have lost capacity to make decisions about my medical treatment, please check the validity and applicability of this ADRT. If it is valid and applicable, please ensure that you act on it, as it is a legal document.

Please help to share this information with relevant colleagues involved in my treatment and care, who need to know about this. Please also check if I have made any other statements about my preferences or wishes that might be relevant to my advance decisions.

2. My condition

In relation to my health problems, I have been diagnosed with the following –

This affects me in the following ways –

3. My advance decisions

The following instructions state which treatments I wish to refuse and the precise circumstances in which each action will apply.

<p>Unless stated otherwise below, I confirm that the following decisions to refuse treatment are to apply even if my life is at risk as a result.</p> <p>(Please tick this box if you agree with this statement): <input type="checkbox"/></p>	
I wish to refuse the following specific treatments –	In these circumstances –

4. My signature (Please print form to sign)

My signature (or nominated person):	Date of signature:

5. Witness signatures (Please print form to sign)

Witness statement:	
I testify that the maker of this Advance Decision to Refuse Treatment signed it in my presence and made it clear that they understood what it meant. I do not know of any pressure being brought on this person to make such an advance decision and I believe it was made by their own wish. As far as I am aware, I do not stand to gain from this person's death.	
First witness –	
Name:	Address:
Signature:	
Date signed:	Telephone number:
Second witness – (only one witness is required, but it is preferable to have two)	
Name:	Address:
Signature:	
Date signed:	Telephone number:

6. Important contacts

If you need to discuss my wishes, the person I would like you to contact first is –	
Name:	Relationship:
Address:	Telephone:
<p>I give permission for this document to be discussed with my relatives and carers. (Please tick this box if you agree with this statement): <input type="checkbox"/></p>	
I have discussed this document with the following health and social care professional –	
Name:	Profession/job title:
Contact details:	Date document was discussed:
My General Practitioner (GP) is –	
Name:	Telephone number:
Address:	

These people have a copy of this ADRT or have been told about my advance decisions –		
Name:	Relationship:	Telephone number:

7. Review dates

I confirm that the decisions in this document are current and apply unless I specifically state otherwise.

I have reviewed this ADRT on the following dates:

Review 1 –	
My signature:	Date of review:
Review 2 –	
My signature:	Date of review:
Review 3 –	
My signature:	Date of review:
Review 4 –	
My signature:	Date of review:

8. Further information

The following information is important to me, but does not directly relate to my Advance Decision to Refuse Treatment –

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Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

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Version: 1

