



## 9: Advance care planning and advance decisions

**This section explains how advance care planning and Advance Decisions to Refuse Treatment (ADRT) can support your future care.**

The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: [www.mndassociation.org/eolguide](http://www.mndassociation.org/eolguide)

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



**End of life:**  
A guide for people with  
motor neurone disease

# 9: Advance care planning and advance decisions



This section explains how advance care planning and Advance Decisions to Refuse Treatment (ADRT) can support your future care.

Please be aware that the following pages contain sensitive information. Read this information when you feel ready to do so. You can always return to this section later.

“ Having someone to guide you through at the right time is so important to feel you are controlling something around you, when all feels out of control.”

## Planning for urgent situations

Regardless of any decision-making about your future care, it is important to consider the following questions:

- What will happen if my main carer is unable to support me for any reason?
- Where can I find appropriate care and support if my main carer needs a break (usually called respite care)?
- How do we access emergency treatment out of hours?

### Who can help answer these questions?

Finding out about out-of-hours assistance for care or where to get urgent help in an emergency can seem bewildering. You may worry about which services will be appropriate to your needs. Ask your GP and health and social care team for guidance. Specialist palliative care professionals and hospices will also be able to advise.

Many areas have electronic patient records, including details about end of life care. Where available, you can access your electronic records. Information about care planning can also be shared with relevant services to keep them informed. Ask your GP surgery, hospital or hospice for guidance.

You may find it helpful to ask your local adult social care services for an assessment of your care needs. This may result in care services being arranged to help you, but also gives you the opportunity to find out what to do in difficult situations or emergencies. They can explain how local services work. They should also provide an assessment for your main family carer to see if they will need support.

You can contact adult social care services through your local authority (or in Northern Ireland through a local health and social care trust).

Keep any contact details for out-of-hours or emergency help where they can be easily found if needed.

### Can I do anything else to plan ahead for emergencies?

You may find the following useful:

#### MND Alert Wristband:

a silicon wristband to alert emergency teams that you have MND. It warns that you may be at risk with oxygen and gives a web link to details for professionals.

**MND Alert Card:**

a small card available from the MND Association to keep in your purse, wallet or pocket, to alert hospital staff that you have MND and need specialist help, with space to record key contacts.

**Understanding My Needs:**

a write-on booklet available from the MND Association. This lets you record basic notes about your needs and how you would like to be cared for should you be admitted to hospital or a hospice.

**Carer's Emergency Card:**

these can be carried by a carer to alert someone to your care, in case they are away from home and unable to support you. The cards are usually available from your local authority, who may also provide a registration service to help direct services to you, should an emergency arise.

**Message in a Bottle:**

stickers on your fridge and inside of your front door tell paramedics to look inside your fridge, for a bottle containing essential personal and medical details. Bottles are free of charge and can usually be obtained from your local chemist. You can also find details through the Lions Club. Search for message in a bottle at <http://lionsclubs.co>

**MedicAlert:**

a registered charity that provides an identification system for individuals with medical conditions and allergies. This is usually provided in the form of a bracelet or necklet, which you purchase. The scheme is supported by a 24-hour emergency telephone service. You can find details at: [www.medicalert.org.uk](http://www.medicalert.org.uk)

**See Further information at the end of Part 3: *What do those close to me need to know?* for details of how to access our other items and publications, including resources for carers.**

**Make important documents easy to find:**

If you make advance care plans or advance decisions to refuse treatment (using an ADRT form), ensure these documents are easy to find in an emergency. For example, it is not

advisable to lock them away in a safe, which may be difficult to access when needed. Paramedics and medical teams need to see these to be able to carry out your wishes. If you are using the Message in a Bottle scheme, the bottle may not be big enough to hold all your forms, but you could add a note that you have advance care plan and an ADRT to make them aware.

**See also *Breathing* in Section 4: *What to expect as the disease progresses*, for details about our MND Just in Case Kit (JIC Kit) which can help if you become breathless or have bouts of coughing or choking.**

## Advance care planning

Advance care planning asks you to set out your preferred priorities for your future care. This helps other people to make choices for you should you become unable to make decisions or communicate for yourself.

In other words, what sort of help would you want from health and social care professionals or anyone else involved in your care? These plans would only be used if you became unable to decide for yourself.

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

An Advance Care Plan can cover almost any aspect of your care. Your preferences might include:

- your choices about where you want to be cared for (for example, at home, in hospital, in a nursing home or a hospice)
- how your religious or spiritual beliefs should be reflected in your care
- any special requirements about food or drink
- how you would like particular aspects of care to be delivered (for example, whether you prefer a bath or a shower)

- who you would like to provide personal care
- decisions about the type of treatment you do or do not want
- how you would prefer to be cared for in an emergency if you are unable to communicate for any reason
- your wishes about practical issues (for example, if you own a pet you might want to provide contact details for the person who has agreed to care for your pet).

## Location of care

You may have a preferred place for end of life care or death. This may be very important to you.

**“ The thing is, it’s about preparing for a good death... I want to be somewhere where people are used to having people die. At the hospice, the staff have support too, and that’s critically important.”**

You may want to be in specialist surroundings or you may want to stay at home, unless you need emergency treatment.

Some people, who know and accept their end of life is drawing near, make a statement that they do not wish to be admitted to hospital, even if this means they will not be able to receive treatment that could potentially prolong their life.

Whatever your choices may be, they will be respected where possible. However, preferred locations cannot be guaranteed as:

- your care needs may be too complex to handle in your home or you may be admitted to hospital in an emergency
- there may not be any available beds at the time needed, eg in a local hospice with limited capacity.

## How do I record my plans?

First, ask your GP and/or specialist palliative care professionals for advice on what to

consider. MND can be complex and they can provide guidance based on your symptoms, the speed of your progression, and your personal circumstances and preferences.

You can then record these wishes in an Advance Care Plan (sometimes referred to as an Advance Statement), which can be used to guide your care should you become unable to communicate for any reason. This is not a legal document, but health and social care professionals can use it to support you.

**“ An Advance Care Plan is a written statement that conveys your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.”**

NHS England, End of Life Care

Some areas are now using standard forms for advance care planning. Recording your plans on the preferred document can help professionals feel confident about its use. Ask your GP or palliative care team for guidance.

You can tell people about your wishes, but writing them down in an Advance Care Plan ensures that anyone involved in your care is clear about what you want, even if you become unable to communicate for any reason.

Your Advance Care Plan can also name who you would like to be consulted about your care, such as your main carer. Health and social care professionals will do their best to consult them. This is not the same as someone having Lasting Power of Attorney to make decisions on your behalf, where there is a legal requirement for professionals to consult the person you have appointed.

**See later heading in this section *Do I need anyone to act on my behalf?* for details about Lasting Power of Attorney in England and Wales, and Enduring Power of Attorney in Northern Ireland.**

An Advance Care Plan can also include preferences about treatment and future withdrawal of treatment, but it is not legally binding. This means that withdrawal of life-sustaining treatment may not be actioned using an Advance Care Plan. However, you can complete an Advance Decision to Refuse Treatment (ADRT) to cover these instances if wished. An ADRT is legally binding if valid and applicable.

## Advance Decision to Refuse Treatment

MND can affect speech and communication, and in some cases the ability to reason. As a result, you may feel anxious about the possible lack of personal control over treatments as the disease progresses.

See the heading *Changes to thinking and reasoning* in Section 4: *What to expect as the disease progresses*.

If you are 18 or over, an Advance Decision to Refuse Treatment (ADRT) is a document that you use to record specific decisions about the refusal or withdrawal of treatments, and when you would want this to happen. Your advance decisions can then be used to guide others, should you become unable to make choices or communicate. An ADRT is sometimes referred to as a 'Living Will' or an 'Advance Directive'.

When you sign the ADRT, you must be able to make and communicate reasoned decisions for it to be valid (known as having mental capacity and governed by the Mental Capacity Act). If you are concerned about this, ask your health and social care team for guidance or consult a solicitor for advice.

See later heading in this section, *Do I need anyone to act on my behalf? for more details about mental capacity*.

In England and Wales, an ADRT is legally binding, if it meets the requirements of the Mental Capacity Act. It will only be used if valid and applicable for the specific circumstances stated in the ADRT, and only if you lose the ability to make and communicate decisions in person.

In Northern Ireland and Scotland, ADRTs are governed by common law rather than legislation, which means that an ADRT is not legally binding. However, health and social care teams should respect your instructions where possible.

### Do I have to do this?

Whether to have an ADRT or not is your choice. You may feel that refusal of treatment is the right course for you:

“ I have an ADRT because it was important to me that medical interventions do not prolong life and I didn't want to leave loved ones with the burden of trying to decide what treatments I would have wanted and what I wouldn't have wanted. I didn't want anyone to be left with feelings of 'have I done the right thing?'"

However, you might have a different view:

“ I wanted to ensure that doctors understand I have a good quality of life and wish them to do all they can to preserve this."

The decisions you make will depend on your own outlook, views, responses to the disease and how discussions with your family and professionals influence your views.

If you find it difficult to be specific about refusal or withdrawal of treatment and decide not to have an ADRT, you can still record what you feel is important about your future treatment in an Advance Care Plan. Although this is not legally binding in the same way as an ADRT, it can help guide decision-making, should you become unable to decide or communicate for yourself.

## What do I need to include in my ADRT?

Always discuss your ADRT with your GP or neurologist to ensure you are completing it correctly. They can also advise on specific circumstances. For example, you may want to refuse antibiotics for a chest infection, but not for a problem such as a bladder infection.

Your ADRT must be in writing and include the following:

- your name and address
- the name and address of your GP
- a clear statement about which treatments you would want to refuse or withdraw, and in which circumstances
- a declaration that your decisions apply, **'even if my life is at risk'** by refusing a treatment that may be life-sustaining (the phrase in bold must be used)
- your signature or the signature of another person on your behalf, carried out in your presence and under your direction
- the dated signature of at least one witness
- the name, address and telephone number of any person you have nominated to be consulted about your wishes
- any review dates with a signature (as your views, illness and treatment may change over time)
- who has copies (eg doctor, hospital, family, ambulance service).

**See Further information at the end of Part 3: What do those close to me need to know? for details about our ADRT information sheet. This includes an example form with completed entries and a blank form for you to fill in if required.**

**“ Key point: acceptance. I was already thinking about it when the doctor mentioned it, so it wasn't a problem. It gives me peace of mind to have it all written down.”**

If you appoint someone to make care decisions on your behalf through a Lasting Power of Attorney (LPA), and you include life sustaining care, it will invalidate any previous ADRT. Your appointee can still use your ADRT as a guide, but they will have authority to make decisions for you, even if different to your previous ADRT. However, if you make a new ADRT after the LPA, then it cannot be overruled by the LPA.

If you LPA only appoints someone to make financial decisions, your previous ADRT remain valid.

This does not apply if the LPA only appoints someone to make financial decisions, in which case your ADRT will still be valid.

**See later heading in this section *Do I need anyone to act on my behalf?* for details about Lasting Power of Attorney in England and Wales, and Enduring Power of Attorney in Northern Ireland.**

## What decisions can be included in an ADRT?

An ADRT covers your decisions about the refusal or withdrawal of treatment, including the precise circumstances in which you want this to happen.

Withdrawal of life-sustaining treatment might mean stopping something that is no longer helping or has become a burden. A natural death may follow, although not always straight away. Symptoms can be eased with medication to reduce anxiety, pain or discomfort.

### Example:

you may wish for existing or future breathing support to be withdrawn at a particular point. You would need to be specific about the circumstances for the withdrawal, so that your family, carers and health professionals know when to act, should you be unable to communicate this yourself.

**See Section 4: What to expect as the disease progresses for details about interventions and withdrawals in the later stages of MND.**

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

### What decisions *cannot* be included in an ADRT?

An ADRT cannot be used to:

- decline basic nursing care required to keep you comfortable
- request anything (eg medication) to deliberately cause or accelerate death
- determine what should happen following your death
- ask for new treatments to begin.

You can of course ask for new treatments before the ADRT becomes valid. These will depend on timing and your condition. Try to discuss all options with relevant specialists, to help you make informed decisions.

### What happens if I change my mind?

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

You can review and amend your ADRT at any time, as long as you are considered to have mental capacity (the ability to make clear and reasoned decisions). If you do change your mind, you need to inform everyone that has a copy of your previous ADRT and ask them to destroy it. If you make a new one, ensure they have the new copy. It is useful to review the ADRT on a regular basis to see if anything

needs amending. Add a date and signature to record when it was last reviewed/revised. Copies of the updated version can then be distributed to the people that hold the ADRT.

Any direct communication from yourself will have more authority than the ADRT, so you can indicate a change of mind at any point. In other words, an ADRT cannot be used to force you to take action against your wishes.

**“ He thought he wouldn’t want to live confined to a wheelchair and attached to a non-invasive ventilation machine, but he felt completely different when he was in the situation. Even though he sat in his chair all day, every day, he always found something positive to live for. A week before his death he announced, ‘I still enjoy my life!’”**

### Who needs to know about my ADRT?

If you have made an ADRT, your family, main carer and the key health and social care professionals involved in your care should be made aware of this. Ideally, your GP, neurologist and main carer should hold a copy of the document and the signed original should be kept safe, but easy to locate if needed.

Your original ADRT needs to be easily accessible if decisions about withdrawal of life-sustaining treatment are to be carried out, as in some cases professionals may ask for the original as legal proof of your intent. For example, paramedics may need this if there is an emergency call-out.

**“ 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.”**

## What does DNACPR mean?

DNACPR in full means: Do Not Attempt Cardiopulmonary Resuscitation.

Cardiopulmonary arrest is when your heart stops beating and your breathing stops. Cardiopulmonary resuscitation (CPR) is the procedure used to try and restart your heart and breathing. The decision to attempt CPR is made by the clinical team in charge of your care. There may be a reason why CPR is unlikely to work depending on your condition and circumstances, in which case it may not be attempted.

Neither you nor your family can insist that CPR be tried, but you can refuse CPR with a DNACPR. This may result in members of your health and social care team making a recorded decision not to attempt resuscitation. Ask your health and social care team about how to arrange this.

A DNACPR should not be placed on your record without your knowledge. The clinical team must involve you in any decisions about resuscitation, unless there is good reason not to. For example, where doing so would cause you harm or you do not want to be involved in the discussion.

If you do have a DNACPR, you can still ask for, and expect to receive, the best possible medical and nursing care to treat MND and any other conditions, and to ensure your comfort.

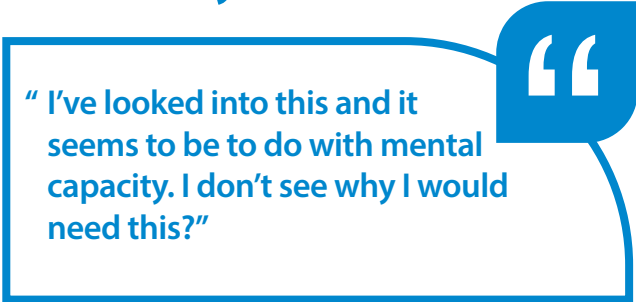
### Will the DNACPR always apply?

The 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 your heart or breathing stop during that short time.

If you have a DNACPR, it will be respected in most instances, however, it is not legally binding. For example, a clinician might attempt resuscitation if something other than MND caused your heart or breathing to stop, such as an accident.

In England and Wales you can include a refusal of CPR in your ADRT. This instruction will be legally binding, as long as the ADRT is correct and valid. You must include clear instructions about when you wish this instruction to be applied. Think carefully about this, as you may wish to allow for some flexibility for your health and social care team to make decisions in unexpected circumstances.

## Do I need anyone to act on my behalf?



“ I’ve looked into this and it seems to be to do with mental capacity. I don’t see why I would need this?”

Mental capacity means the ability to make and communicate your own decisions, based on reason. According to the Mental Capacity Act 2005, a person is unable to make a decision on their own behalf if they cannot:

- understand the information relevant to the decision
- retain that information long enough to be able to make the decision
- use or weigh that information as part of the process of making the decision, or
- communicate their decision (by talking, sign language or any other means, including responses such as blinking an eye).

For some people, MND may affect the ability to make or communicate decisions as the disease can cause:

- problems with speech and communication, making it difficult to clearly express your wishes and preferences
- changes to thinking, reasoning and memory (this may not happen and is usually mild, but a small number of cases are more severe or involve a type of dementia)
- the possibility of reduced consciousness in the final stages.



For these reasons, you may need someone to act on your behalf and they will be expected to act in your best interests. However, all efforts should be made to enable you to communicate your own wishes, including the provision of communication aids if required.

Even if you have problems making complex decisions, you may still be able to make certain choices, such as what you want to do during the day.

An Advance Care Plan can help guide most aspects of end of life care, but is not legally binding. An ADRT is legally binding, if valid and applicable. This can help ensure your wishes for refusal of treatment are respected, if you become unable to make or communicate your decisions.

You can also legally appoint one or more representatives (whether a family member, friend or professional) to make financial or healthcare decisions on your behalf through Lasting Power of Attorney. This is governed by the Mental Capacity Act 2005.

**See later heading in this section, *Enduring Power of Attorney (EPA) – Northern Ireland.***

You may be assessed for mental capacity (the ability to make reasoned decisions on your own behalf) when making any major decision. This is usually about finance or care, but can involve other choices. It may include decisions about life-sustaining treatment. You may also be assessed if passing authority for decision making to someone else.

Assessment takes place with a health or social care professional, for each relevant situation (a single assessment cannot cover all purposes).

## **Lasting Power of Attorney (LPA) – England and Wales**

Lasting Power of Attorney allows a trusted friend or relative to make decisions on your behalf if you are unable to decide or communicate for yourself.

This requires a legal document to be registered with the Office of the Public Guardian (OPG), for which you will be charged a fee. For many, this may be an expensive option and we recommend that you find out about the current cost through the OPG.

**See Section 16: *Useful organisations for contact details of the Office of the Public Guardian (OPG).***

There are two types of Lasting Power of Attorney:

- for property and finance (should you agree, this can be used by the appointed person even if you can still make decisions yourself)
- for health and personal welfare (which can only be used if you become unable to decide or communicate for yourself. You must state if you wish this to apply to decisions about life-sustaining treatment).

It is important to note that Lasting Power of Attorney for health and personal welfare gives someone authority to make decisions about your care and treatment. This invalidates any previous ADRT you may have made, as the LPA holds the higher authority. However, it is still worth maintaining your ADRT, as the person who has Lasting Power of Attorney can refer to this if they need to make decisions on your behalf. If you appoint someone to only make property and financial decisions, your ADRT will remain valid. If you create a valid and applicable ADRT after the LPA, the LPA cannot invalidate it.

The forms to create Lasting Power of Attorney can take time to complete. A legal professional can do this for you, but they will charge you (in addition to the Lasting Power of Attorney fee).

## **Enduring Power of Attorney (EPA) – Northern Ireland**

In Northern Ireland, Power of Attorney is known as an Enduring Power of Attorney (EPA) and is registered through the Office of Care and Protection. This only enables decisions on your behalf concerning property and finance, not personal welfare or care related matters. As a result, your ADRT cannot be overruled by Enduring Power of Attorney.

Please note, the Mental Capacity Act 2005 does not apply in Northern Ireland.

**See Section 16: *Useful organisations for contact details of the Office of Care and Protection. Also for MND Scotland if you need guidance for Scotland.***

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MND Association  
PO Box 246, Northampton NN1 2PR  
Tel: 01604 250505  
Website: [www.mndassociation.org](http://www.mndassociation.org)

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