



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

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

Telephone: **0808 802 6262**

Email: 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, including guidance on other alerts and power of attorney.

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

When planning ahead, consider the following:

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

Who can help answer these questions?

Finding out-of-hours assistance, urgent care support or appropriate emergency help at short notice can feel stressful. Ask your GP or health and social care team for guidance. Specialist palliative care teams and hospices can also advise.

You may be able to access your patient records online, including end of life care. Keep relevant services informed of your care plans. Ask your GP, hospital or hospice for guidance.

Ask your local adult social care services for an assessment of your care needs. This may result in care services being arranged, but also guidance about urgent situations or emergencies. Keep contact details for out-of-hours or emergency help close to hand. Your carer can also have their needs assessed.

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

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 from the MND Association for your purse, wallet or pocket, to alert hospital staff that you need specialist help for MND, with space for key contacts.

Understanding My Needs

A write-on booklet from the MND Association to help you record your care needs and preferences for care workers or medical staff.

Carer's Emergency Card

For a carer to carry in case they are away from home and unable to support you. It provides an alert that you need support. The cards are usually available from your local authority, who can help should an emergency arise.

Message in a Bottle

Stickers on your fridge, and inside your front door, tell paramedics to look for a bottle in your fridge, that contains personal and medical details. Bottles are free from your local chemist. For details, search for message in a bottle at <http://lionsclubs.co>

MedicAlert

Bracelets or necklets that you can purchase and wear to identify your medical condition or allergy. The scheme is supported by a 24-hour emergency telephone service. See: www.medicalert.org.uk

See *Further information at the end of Part 3: What do those close to me need to know?* to access our related resources.

Make important documents easy to find

Make documents like Advance Decisions to Refuse Treatment (ADRT) easy to find in an emergency. Don't lock them in a safe, as paramedics need to see these to carry out your wishes. If you use the Message in a Bottle scheme, you could add a note in the bottle about where to find your medical documents.

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

Advance care planning

An advance care plan records your choices for future care, as guidance in case you become unable to make decisions or communicate for yourself. You can include what you'd want from health and social care professionals or anyone involved in your care.

" 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
- special food or drink requirements
- how you want care delivered, such as, 'I prefer baths to showers'.
- who you would like to provide personal care (for example, would you want this to be a male or female to meet cultural or religious needs?)
- guidance about treatments you do or don't want
- your preferences for emergency care, in case you cannot communicate for any reason
- practical guidance (for example, contact details for someone who has agreed to care for your pet).

" It's vital to have discussions about advance planning, at the right time."

Location of care

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

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

“ 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.”

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
- you may be admitted to hospital in an emergency
- a bed may not be available at the time, as with limited space in a hospice.

How do I record my plans?

Ask your GP or specialist palliative care team what to consider. They can provide guidance based on your symptoms, speed of progression, circumstances and preferences.

You can then record your care wishes in an Advance Care Plan (sometimes referred to as an Advance Statement). This is not a legal document, but your guidance can be used by anyone involved in your care if you become unable to communicate for any reason.

Ask your GP or palliative care team if there is a standard form for advance care planning in your area. Using a preferred document can help professionals feel confident about its use.

An Advance Care Plan can include preferences about treatments, but it isn’t legally binding. Professionals cannot use it to action withdrawal of life-sustaining treatment. If you want instructions about treatment legally covered, you need to complete an Advance Decision to Refuse Treatment (ADRT).

An ADRT is legally binding if valid and applicable in the circumstances (see next heading).

You can name who you want to be consulted about your care in your Advance Care plan, such as your main carer. Health and social care professionals will do their best to consult them, but neither an Advance Care Plan or ADRT form enables someone to make decisions on your behalf. For this, you need to legally grant someone power of attorney. Once done, 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.*

Advance Decision to Refuse Treatment

MND can affect speech and communication, and in some cases thinking and behaviour. As a result, you may feel anxious about the possible loss 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) form can help you record refusal or withdrawal of treatments, and when you would want this to happen. Your advance decisions can then guide others, if you become unable to make choices or communicate. An ADRT is sometimes referred to as a ‘Living Will’ or ‘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 on *What is mental capacity and why is it assessed?*

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.

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 grant someone Lasting Power of Attorney (LPA) to make health care decisions on your behalf, and you include authority for life-sustaining treatments, the LPA will invalidate any previous ADRT. This means they can make decisions different to the instructions in the ADRT, if they feel that would be in your best interests. Ensure the person with power of attorney has a copy of your ADRT, as they can still use this as a guide. However, if you make a new ADRT after the LPA, then it cannot be overruled by the LPA.

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.*](#)

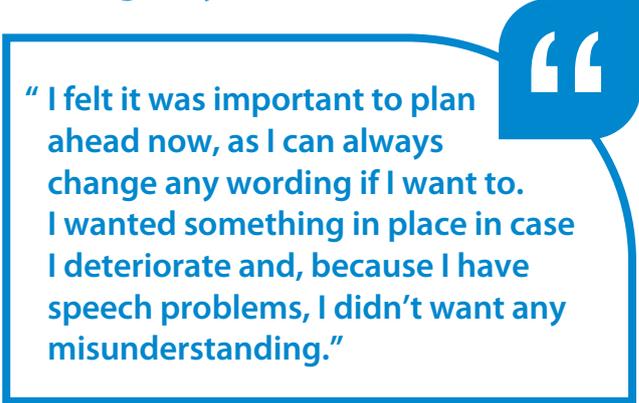
What decisions *cannot* be included in an ADRT?

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 amend your ADRT at any time, as long as you are considered to have mental capacity (the ability to make clear and reasoned decisions). It is useful to review your ADRT on a regular basis in case you want to make changes. Add a date and signature to record when it was last reviewed or revised.

If you do make changes, send a new copy to everyone who has your previous ADRT and ask them to destroy their old copy. See *Who needs to know about my ADRT?* on the next page.

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, then your family, main carer, anyone granted power of attorney and your key health and social care professionals should be made aware of this. Ideally, your GP, neurologist, main carer and anyone holding power of attorney for you should be given a copy of the document. Keep the signed original somewhere 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. The previous wording of Do Not Resuscitate (DNR) is no longer used.

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 refusal of CPR in your ADRT, which is legally binding if the ADRT is correct and valid. You must be clear about when you’d want this instruction to be applied, but you may want to give health professionals some flexibility for decisions in unexpected circumstances, such as an accident.

What is mental capacity and why is it assessed?

Mental capacity describes our ability to make and communicate our own decisions, based on reason. This means being able to:

- understand the information relevant to a 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
- communicate your decision (by talking, sign language or other means, such as blinking an eye).

You may be assessed by a health and social care professional for mental capacity when making major decisions. These could include choices about finance, care, life-sustaining treatment or permission for someone to make decisions on your behalf. You may be able to make some decisions but not others – and as mental capacity can change, you may be assessed more than once.

Find the Acts that govern mental capacity at www.legislation.gov.uk Search for Mental Capacity Act 2005 for England and Wales, and Mental Capacity Act 2016 for Northern Ireland.

What is deprivation of liberty?

When someone is in hospital or a care home, restrictions may be imposed if their mental health puts them at risk. As a result, freedom to leave or move around may be limited, known as deprivation of liberty. Separate authorisation must be granted for deprivation of liberty during care in the community.

Any action must be in the best interests of the individual and safeguards are governed within the Mental Capacity Acts shown above. Search for *deprivation of liberty* at www.gov.uk in England or Wales, or www.health-ni.gov.uk in Northern Ireland for more information.

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?”

For some people, MND can cause one or more of the following:

- problems with speech and communication
- changes to thinking and behaviour (if affected, these changes are usually mild, but can get worse over time, and 1 in 10 people with MND may have more severe changes with a form of dementia)
- reduced consciousness in the final stages.

For these reasons, you may need someone to make decisions in your best interests. Even if you have problems making complex decisions, you can still make certain choices, such as what you want to do during the day.

All efforts should be made to help you communicate your own wishes, including communication aids if required.

As explained in this section, a written Advance Care Plan can help you guide your care, but it is not legally binding. An ADRT can help ensure your wishes are respected for refusal of treatment - this is legally binding, but only if valid and applicable in the circumstances.

With an Advance Care Plan or ADRT, you set out what you want to happen. But you may also have a preference about who should act in your best interests, if needed. You can do this by legally appointing a family member, friend or professional to make decisions on your behalf. This is called power of attorney and allows the appointed person to make choices for you, even if something unexpected happens. They should take into account any guidance you have provided for them.

How do I grant someone power of attorney?

Power of attorney allows one or more individuals to make decisions on your behalf, should they agree to this role. This permission is granted by you in a legal document. In England and Wales this is known as a Lasting Power of Attorney (LPA). Northern Ireland uses Enduring Power of Attorney (EPA) instead, as explained below.

You can find forms to create an LPA or EPA online, but there is a lot to think about and the form must be registered before it can be used. Legal advice is recommended, as power of attorney is complex and cannot be changed after creation (unless you decide to withdraw the document and create a new power of attorney). A qualified legal professional can advise on the creation, registration, and use of powers of attorney. This can help avoid problems and provide safeguards to protect you and the person who you have given power of attorney.

There will be a charge for legal advice, in addition to the registration fee for power of attorney.

Lasting Power of Attorney (LPA) – England and Wales

In England and Wales, an LPA must be registered with the Office of the Public Guardian (OPG), where you can check the fee for this service:

www.gov.uk/government/organisations/office-of-the-public-guardian

There are two types of LPA:

For property and finance

This enables someone to make decisions about your property and financial affairs and is the only way to give this authority. Without this, your loved ones may face difficulties and possibly financial loss if you become unable to manage your affairs. This type of LPA is recommended, even if you don't want to give permission for health and personal welfare decisions. Should you agree, it can be used by the person you have granted power of attorney, even if you can still make decisions yourself.

For health and personal welfare

This enables someone to make choices about your care and treatment, but only if you can no longer make decisions or communicate for yourself. You must state if you want this to include decisions about life-sustaining treatment, but this needs to be specific.

An LPA for health and personal welfare invalidates any previous ADRT you may have made. However, it is still worth maintaining your ADRT to provide guidance to the person who you have granted power of attorney. If you create a valid ADRT after the LPA, the LPA cannot invalidate it. If you appoint someone to only make property and financial decisions, your ADRT will also remain valid.

Power of attorney is governed by the Mental Capacity Act 2005 in England and Wales (see previous weblink).

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

Enduring Power of Attorney (EPA) – Northern Ireland

In Northern Ireland, an EPA is used instead and recommended to ensure your affairs can be managed if you become unable to do this. It may help your loved ones avoid difficulties. An EPA must be registered through the Office of Care and Protection (OCP), where you can check their fee for this:

www.nidirect.gov.uk/contacts/contacts-az/office-care-and-protection

Search for *Enduring Power of Attorney (Northern Ireland) Order 1987* and the *Mental Capacity Act (Northern Ireland) 2016* at:

www.legislation.gov.uk to find out more about legal governance for power of attorney in Northern Ireland.

See Section 16: Useful organisations for contact details of MND Scotland if you need guidance for Scotland.

Document dates:

Revised: March 2021

Next revision: March 2024

Version: 1 in this revision period

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Registered Charity No. 294354

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