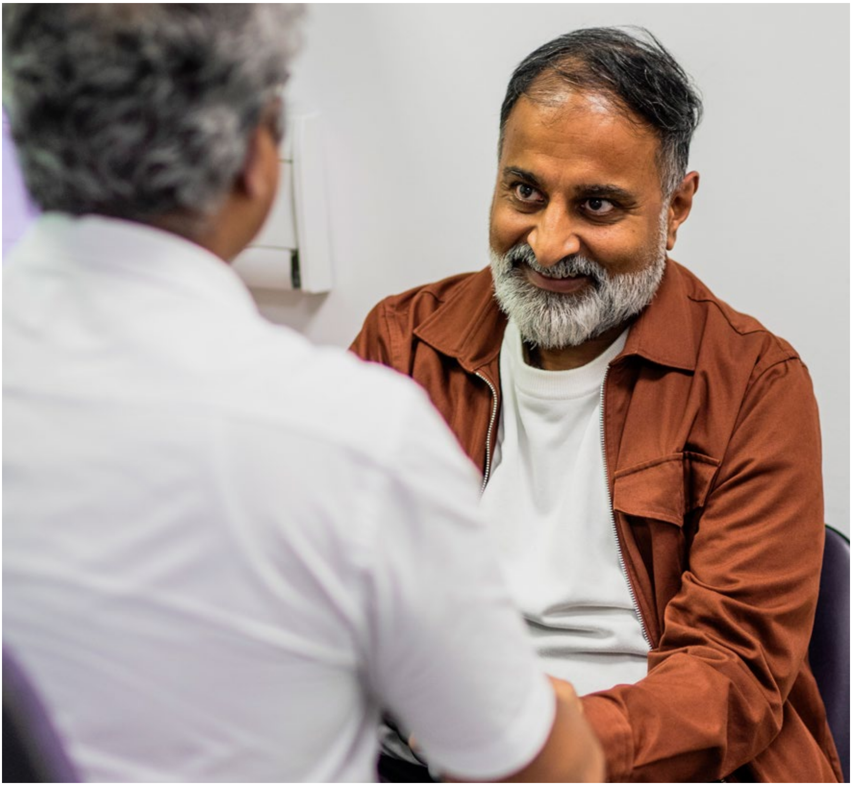
MND Association | For professionals

Advance care planning for MND



About Motor Neurone Disease

Today, six people

will be told they have MND and six people will die from the disease. There is no cure.

MND is a fatal, rapidly progressing disease.

It affects the nerves in the brain and spinal cord that control muscles.

A third of people will die within a year of diagnosis.

More than half will die within two years.

People may lose movement, speech, swallowing and breathing.

This affects quality of life for them and those around them.

MND doesn't discriminate.

It affects people from all backgrounds and at all ages.

People with MND may experience changes in thinking and behaviour.

Some develop frontotemporal dementia, with more severe changes.

MND affects everyone differently.

Symptoms progress at different speeds and a different order for everyone.

Contents

Introduction

Motor neurone disease (MND) is a progressive and terminal disease that results in degeneration of the motor neurones, or nerves, in the brain and spinal cord. There is no cure for MND. Although the condition itself is unpredictable, the terminal prognosis is not.

MND reduces life expectancy, with a third of people with the disease dying within a year of diagnosis, and more than half dying within two years. The course the illness takes varies between individuals but when facing uncertainty, supporting people living with MND to make plans for the future can be reassuring, empowering, or even life-affirming.

People with MND face unique challenges in making decisions about their care and treatment due to the unpredictable and debilitating nature of the disease.

Advance care planning (ACP) is a proactive process that involves discussing, documenting, and respecting the wishes and preferences of people with MND regarding their future care. ACP involves making informed decisions about personal, legal and financial issues as well as future healthcare preferences, considering the progressive nature of MND.

Talking about ACP is part of the role of every professional working with people with MND, so it is important not to assume that someone else has already had these discussions.

By supporting people with MND in expressing their wishes and values, ACP ensures person-centred care that respects their autonomy. It also helps family members by facilitating discussions that may be challenging, and providing clarity over actions to take in the future if the person loses the ability to make decisions for themselves.

This booklet aims to provide all health and social care professionals with knowledge and practical strategies for effectively facilitating advance care planning for people with MND. This will support professionals to provide holistic and compassionate person centred care that honours people's preferences throughout their MND journey.

Information for professionals

Booklet – A professionals' guide to end of life in MND

Information for people with or affected by MND:

Booklet – End of life: a guide for people with MND
Information sheet 14A – Advance Decision to Refuse Treatment (ADRT) and advance care planning
Information sheet 8C – Withdrawal of ventilation with MND
Understanding my needs – A record of someone's needs to help professionals provide appropriate support.

See page 39 for details of how to order publications.

Benefits and challenges of advance care planning

ACP offers advantages for people with MND, their families, carers and health and social care professionals, but can also present some difficulties. By understanding the benefits and challenges, professionals can provide optimal support during ACP for people with MND.

Benefits of advance care planning

Empowerment and autonomy

ACP empowers people with MND to actively participate in decisions regarding their care, ensuring that their wishes and values are respected wherever feasible. ACP provides people with MND the opportunity to carefully consider their treatment options, potential outcomes, and personal values in advance.

By having these discussions and documenting their preferences, people can make more informed decisions about their future care, leading to a greater sense of control and satisfaction with the support received.

Person-centred care

ACP promotes person-centred care by tailoring treatment options to align with the person's goals, values, priorities and treatment preferences. This reduces the likelihood of receiving unwanted or unnecessary interventions and promotes care that is consistent with their goals and quality of life priorities.

By having a conversation, you also allow exploration of ideas, and may present the person with options that had not previously been considered.

Reduced decision-making burden

ACP can alleviate the burden on family members and loved ones who may otherwise feel responsible for difficult decisions.

By documenting their preferences in advance, the person can provide clarity and guidance to decision-makers, relieving them of the responsibility of guessing their wishes during challenging times. It can also help during the grieving process after the person has died, as the family can feel reassured that what was done was in line with the person's preferences where possible, including end of life care.

Where a person has lost capacity to make decisions relating to a medical treatment, decisions made by healthcare professionals in best interests and appointed power of attorneys can be guided by statements made in an advance care plan – see page 21.

Improved continuity of care

ACP provides clear guidance to healthcare teams, ensuring that consistent care is provided across different settings and over time, promoting continuity of care.

When people have documented their preferences, healthcare professionals can access this information and honour the person's wishes, regardless of where the care is being provided. This ensures consistent and personalised care.

Improved communication and collaboration

Thinking about ACP encourages open and honest communication between people, their families, carers and professionals. These conversations, which may help create the person's ACP, foster a collaborative approach to care, allowing for shared decision-making and a better understanding of the person's needs and wishes.

It also promotes stronger relationships and trust between people with MND and professionals involved in their care and can reduce the need to ask the same questions repeatedly, for example when someone goes in and out of hospital.

A multidisciplinary approach involving professionals from a range of disciplines involved in the person's care can ensure all aspects of the person's needs and support are accounted for.

Challenges of advance care planning

Emotional and psychological considerations

ACP discussions can be distressing for people with MND and their families, given the sensitive nature of talking about progression, changing needs and end of life. Some people choose not to engage, or may need several conversations before making decisions.

Even when decisions are not made, these discussions remain valuable. They can help the person explore what matters most and may lead to more formal planning over time.

If someone declines ACP, ask permission to revisit the conversation later. Be alert to cues or trigger points, such as hospital admission. Approach all discussions with sensitivity and empathy, and keep checking what is most important to the person until they feel ready to engage further.

Information for people with or affected by MND:

Booklet – Emotional and psychological support

See page 39 for details of how to order publications.

Communication barriers

As MND progresses, people may experience difficulties in verbal and physical communication. It can be helpful to have ACP discussions before the person's speech is affected if possible.

If speech has already been affected or lost, there are many ways to effectively communicate from low tech to high tech solutions.

Additional care, skill and time may be needed to ensure that the person living with MND has the opportunity to take part in these discussions. A speech and language therapist can help to establish the best way for the person to communicate their wishes.

Information for professionals

Booklet — Communication, speech and language support
Information sheet P10 — Voice banking

Information for people with or affected by MND:

Information sheet 7C — Speech and communication support
Information sheet 7D — Voice banking

See page 39 for details of how to order publications.

Ethical dilemmas

A significant challenge in ACP is balancing the importance of respecting preferences with the fact that some interventions and approaches will not be suitable or available to everyone who would prefer to have them.

Professionals must navigate complex ethical dilemmas, balancing the benefits and burdens of treatments, questions of fairness and resource allocation, and the person's values and preferences.

The responsibility to weigh these factors can be emotionally and intellectually demanding. It can be helpful to involve palliative care professionals who will have a deeper understanding and experience of these issues. They may be able to offer advice, or offer support to the person with MND.

Limited awareness and understanding

Variable knowledge and awareness of ACP among both healthcare professionals and people with MND can be a barrier to effective ACP. Professionals may be unfamiliar with the importance and practical aspects of ACP, while people with MND may lack knowledge of their options or the significance of documenting their preferences.

Professionals new to ACP should actively seek out training opportunities or mentorship from experienced professionals in the field. Enhancing knowledge and understanding can help professionals confidently engage in discussions and guide people with MND through the process.

When introducing ACP to people with MND, ensure information is clear and accessible. Written resources and educational materials can supplement these discussions and help people with MND and their families understand the importance and benefits of ACP.

Cognitive change and frontotemporal dementia

MND can cause cognitive and behavioural changes in some people. For most, these changes are mild and do not significantly affect daily life or decision-making. However, some people with MND develop frontotemporal dementia, which can have a major impact on their ability to make certain decisions.

Professionals should be aware of the potential for cognitive change during advance care planning discussions and adapt their approach where needed. Using simple language, visual aids, breaking complex questions into smaller parts, allowing extra time, and checking understanding can all help the person participate effectively.

If there are concerns about a person's ability to make a specific decision, their mental capacity should be assessed. If they are found to lack capacity, decisions must be made in their best interests in line with the Mental Capacity Act (2005) in England and Wales.
In Northern Ireland, common law follows similar principles. The person should still be involved in discussions as much as possible.

Information for professionals

Booklet — Cognitive change, frontotemporal dementia and MND

Information for people with or affected by MND:

Booklet — Changes to thinking and behaviour with MND

See page 39 for details of how to order publications.

Discussions about advance care planning

It is important that professionals navigate ACP conversations well. It is crucial to be well prepared, and try to anticipate any issues in advance. Professionals should listen to the range of perspectives respectfully, being sensitive to differences of opinion. Maintaining a professional, composed demeanour and refraining from emotional reactions is essential in these conversations.

Be sensitive about the timing of discussions and consider the person's current communication ability, cognitive status and mental capacity. People with MND may expect a professional to raise the topic, or they may indicate, by the questions they use, when they are ready to have information.

Decision-making in MND can be emotionally challenging for both the person and their family. Creating a supportive environment for open and honest discussions is important. Providing emotional support, addressing fears and concerns, and using effective communication can help people navigate complex decisions.

Access to counselling, psychological support and support groups may also help people and families cope with the emotional impact and support their wellbeing.

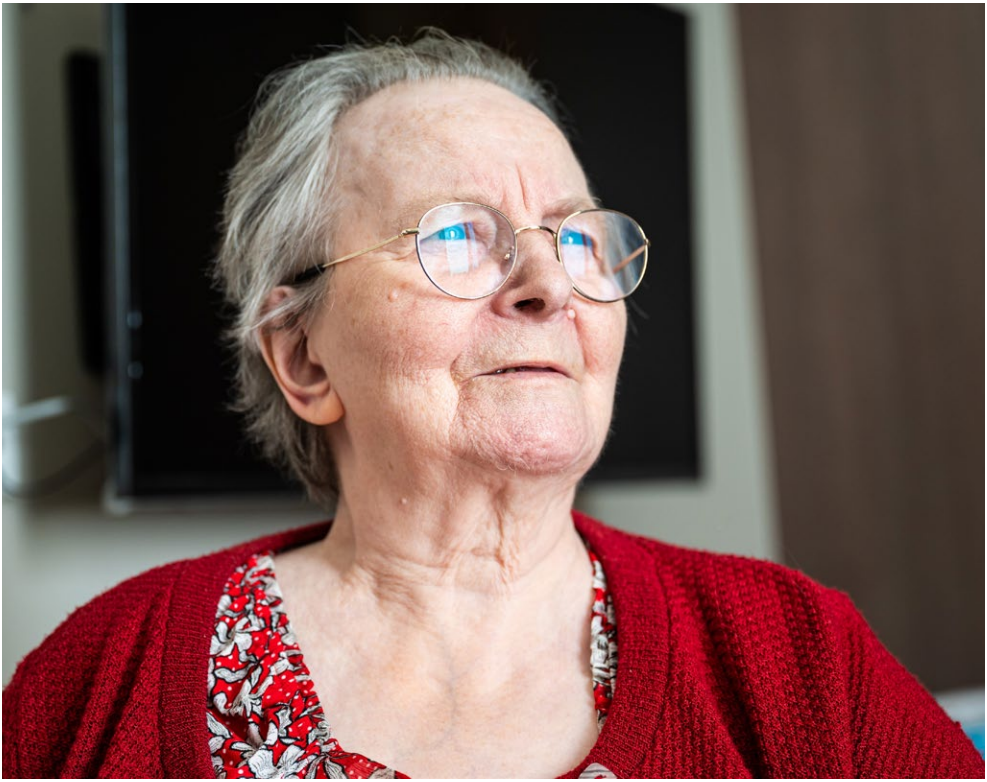
The NICE guideline on MND recommends offering opportunities to discuss preferences and concerns for end of life at trigger points: at diagnosis, if there is a significant change in respiratory function, or if interventions such as gastrostomy or assisted ventilation are needed. Other times may also be appropriate.

It is helpful to know about the treatments that might be discussed to be able to answer questions about them, and to know when and how to get someone else's help or expertise.

Professionals should work within their skills and experience, and recognise that advance care planning discussions may need to take place over more than one visit. Input from specialist team members, or joint clinics and visits, may also be helpful.

Not all advance care planning discussions will lead to a formal document. Informal conversations about future wishes should still be recorded, as they may help guide future decisions if the person loses capacity. These discussions may include topics beyond dying, such as quality of life and extending life.

Advance care planning should take a holistic approach, covering personal, social and spiritual aspects of care as well as medical decisions. Considering the person's circumstances, values and beliefs can help ensure discussions are person-centred and reflect what matters most to them.



Starting conversations about advance care planning

The following suggestions may help you initiate conversations about ACP in a compassionate and supportive manner, helping people and their families navigate the complexities of future care planning and make informed decisions that align with their values and preferences.

Initiate discussions early

ACP discussions should ideally start early in the disease trajectory, soon after diagnosis. This allows people to express their preferences and make informed decisions while they still have capacity to do so.

Starting these conversations in the early stages of the disease helps ensure that the person's wishes and goals are known and can guide their care throughout the progression of MND. Interventions such as gastrostomy should be discussed early, as they may not be possible if the person waits until they have lost a significant amount of weight, or have severe respiratory problems.

Ensure family involvement

Engaging in discussions about future care with family, friends and whoever else is important to the person can involve exploring differences in perspective and can help to ensure that everyone involved shares a common understanding.

It is advisable to discuss any specific needs that family or friends may have if they will be involved in providing care. ACP can help family members understand and respect the person's priorities, enabling clear decision-making and ensuring that the person's wishes are carried out when needed.

It is also important to be aware that some people may not have any family or friends, or may not wish for them to be involved, and may need additional support.

Choose an appropriate time and setting

Wherever possible, select a calm and comfortable environment that allows for privacy and uninterrupted conversation. If the physical environment cannot be altered, acknowledge this and decide if the conversation goes ahead despite this, or reschedule for another time when a better space is available.

Avoid discussing ACP during moments of crisis or stress. Choose a time when everyone involved can give their full attention and engage in open dialogue. Creating a supportive and non-judgmental environment encourages open communication and helps people and their families feel comfortable expressing their concerns, fears, and goals. This will usually take several conversations as there is often a need for reflection or additional information.

Be empathetic and sensitive

Recognise that discussing serious illness and end of life care can be emotional and challenging for people with MND and their families. Approach the conversation with empathy, understanding, and respect for their feelings and beliefs. Use active listening techniques to demonstrate your genuine interest and concern.

Be prepared to provide emotional support and reassurance throughout the conversation. Consider offering to involve a counsellor, chaplain, or other mental health professionals to address emotional concerns, as you would in the course of other clinical encounters.

Involvement of palliative care colleagues may be helpful depending on the setting and resources available.

Use clear language

It is important that the language used, while remaining sensitive, is clear and easy to understand. This means not being afraid to use the words ‘death’ and ‘dying’ instead of euphemisms. If the person with MND and those close to them are ready for it, this clarity is vital.

Introduce the topic gradually

Begin by explaining the purpose and importance of ACP. Emphasise that it is an opportunity to ensure that their wishes and preferences for future care are known and respected, and that these can be changed in the future if they change their mind. Use open questions to encourage dialogue and allow people to express their thoughts and concerns, rather than ticking questions off a list.

Assess readiness

Gauge the readiness of the person and their family members to discuss ACP. Respect their pace and willingness to engage in the conversation. Some people may be hesitant or apprehensive, while others may be more open to discussing their future care. Adjust your approach accordingly and allow people to initiate or guide the conversation as much as possible. Don't feel a need to complete everything at one sitting.

Some people won't want to engage in ACP yet, and some will not want to ever do so. The purpose of ACP is to help people's voices be heard, and if their preference is simply to let professionals make the right decisions when they're needed then they shouldn't be pushed into ACP conversations they do not want.

Provide information and resources

Offer clear and concise explanations about the purpose, process, and benefits of ACP and also the treatments and options the person wants to discuss. Provide educational materials, brochures, or written resources that people can review at their own pace.

These resources can help clarify misconceptions, address common concerns, and provide a starting point for further discussions.

Encourage autonomy and shared decision-making

Emphasise that ACP is about empowering people to make decisions that align with their values, goals, and preferences. Encourage them to express their wishes and actively participate in decision-making. Respect their autonomy by ensuring that their choices are central to the planning process.

Offer professional support

Inform people and their families about the support available from health and social care professionals, including doctors, nurses, social workers and palliative care specialists. These professionals can provide guidance, answer questions and support advance care planning discussions.

Palliative care specialists can offer holistic support throughout the decision-making process. This may include help with emotional and psychological wellbeing, symptom management, and discussions about end of life care.

Respect cultural and religious beliefs

Recognise that cultural and religious beliefs play a significant role in end of life decision-making, whether or not they are obvious at the outset. Be sensitive to the presence of these factors and ensure that the conversation and planning process respect and accommodate any cultural and religious values the person may have.

There may be conflicts between the person's religious beliefs and the ethical and legal duties not to offer treatments, or withdraw treatments that are overly burdensome or of no benefit. It is important to be aware of this, as it has been the basis of some court decisions.

Revisit and update the conversation

ACP is an ongoing process, and preferences may change over time. Encourage people to revisit and update their plans periodically, or in response to changes in their health or circumstances. Remind them that ACP is a flexible tool that can be adapted as needed.

Discussing suicide and assisted suicide

Living with MND can create fear about what will happen as the condition progresses. You may be asked questions about suicide and assisted suicide. People with MND may consider suicide for fear of becoming a burden or due to other concerns about independence or quality of life.

Discussion is crucial in order to explore and understand these issues. It is important to let the person know that thoughts of suicide are not unusual among people with MND and other terminal conditions.

Being able to explore the reasons for these thoughts, and knowing they are not alone can help. If suggestions or solutions to concerns can be provided, thoughts of suicide may subside. Active plans to take their own life should always be taken seriously.

It is important to involve the patient's GP and also consider the use of suicide risk assessment tools to guide you. Often the person wishes to end their lives at a time of their choosing, and this is not necessarily linked to mental illness. Someone being depressed to the point of being suicidal is a mental health issue, separate but maybe related to, thoughts of assisted suicide at some point in the future.

The following information explains what is and isn't allowed within the law (at time of publication). It is not intended to replace legal advice or act as guidance to take any specific action, but simply to provide the facts. Registered health and social care professionals should consult and follow relevant guidance from their regulators and professional bodies.

It is **legal** for someone to:

- take their own life
- refuse life-sustaining treatments which they feel are no longer helpful, or have become a burden. This is not assisted dying.

But it is **not legal** for someone else to:

- encourage another person towards suicide (including advising them how to do this)
- assist them with their suicide.

In your discussions, gently explain the legal situation in the UK and explore alternative actions they can take within the law, for example getting more practical and emotional help, ways to manage their symptoms, refusing life-saving interventions. It is essential that professionals are not seen as colluding with the person, or they could face prosecution.

Do not avoid the discussions or deny the person the chance to talk. If you don't feel able to do it, involve someone who can. Liaise with the person's specialist palliative care team or MND care team for advice and support in managing conversation about suicide and assisted suicide. They may have experience of this.
The Royal College of Nursing (RCN) have produced a useful resource, 'When someone asks for your assistance to die'. Download a copy at **rcn.org.uk/Professional-Development/publications/pub-005822.**

Information to share with people with MND can be found in section 13 of the MND Association's End of life guide (see page 34).

Recording discussions

If discussions are held and decisions are made, these should be clearly documented and shared with all relevant health and social care professionals, including the person's GP. The person with MND should keep copies somewhere easy to access and ensure family and carers know where they are kept. See Planning for urgent situations on page 32.

Wishes, preferences and future care plans should also be recorded on local palliative care co-ordination systems, such as the Gold Standards Framework, Electronic Palliative Care Co-ordination Systems (EPaCCS) and Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). See Recording and communicating decisions on page 31 for further information.

Key ACP decisions and documents

Advance statements

Advance statements, also known as advance care plans, are written documents that allow people to record their wishes, values and preferences for future care. They can help guide healthcare professionals and decision makers if the person is no longer able to communicate their wishes.

Advance statements may include preferences about treatments such as resuscitation, pain management, ventilation and feeding tubes. They can also cover personal, social and practical considerations, including:

- personal care preferences
- assistance with activities of daily living
- preferences for staying at home or moving to a care home
- considerations for comfort
- preferences for visits from family and friends
- involvement in social activities
- engagement with religious or cultural practices
- instructions about who should take care of pets or possessions
- preferences for end of life arrangements, including funeral wishes.

People can express their desires for certain treatments or outline their wishes to refuse certain interventions under particular circumstances. These are not legally binding unless the person has completed an ADRT (see next heading).

Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT), also known as a living will, allows people to refuse specific treatments in advance. It provides legally binding instructions to healthcare professionals about the person's refusal of certain interventions in specific circumstances. People may choose to write these because they feel very strongly about not wanting their lives to be prolonged by receiving a treatment or set of treatments.

ADRTs are legally recognised and can be used to refuse life-sustaining treatments, such as ventilation, cardiopulmonary resuscitation (CPR), or artificial nutrition and hydration.

To be valid, an ADRT must be:

- made by a person with mental capacity
- specific about the treatment(s) being refused
- applicable to the circumstances in which it is invoked.

ADRTs should be completed with the support of professionals with suitable experience to ensure they can be clearly understood, and to avoid doubt about their validity and applicability. An ADRT may be set aside while any doubt is resolved and may therefore fail as an effective refusal.

People considering an ADRT should receive comprehensive information about treatment options, benefits, risks, and potential outcomes. This enables them to make informed decisions based on their values and beliefs.

ADRTs do not expire, but should be regularly reviewed to ensure that they reflect the person's current wishes, and to reduce any doubt about their continuing validity and applicability. Changes in health status or medical advancements may warrant updating the document. Updates may include changes to the refusals, additional refusals, or changes to the specified future circumstances.

It is crucial to communicate the existence of an ADRT to healthcare providers involved in the person's care, including emergency services, hospitals, and primary care providers and to make the document easily accessible during urgent situations.

The contents of a person's ADRT will be considered in best interests decision-making if the person loses capacity and the ADRT is not strictly valid, for example if it is not specific or applicable to the current situation.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

For many people with advanced progressive serious illness, attempts at cardiopulmonary resuscitation are associated with poor outcomes, in terms both of the probability of success and of the harms entailed in the attempt.

Decisions not to attempt CPR are made when it is determined that cardiopulmonary resuscitation would be ineffective, disproportionately harmful, or not in line with the person's wishes or best interests. This decision aims to prevent unnecessary suffering and allow for a natural death.

A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision is a clinical decision to withhold cardiopulmonary resuscitation in the event of cardiac and/or respiratory arrest. It is made by healthcare professionals in consultation with:

- the person unless they would prefer not to participate or would be harmed by this participation or
- someone holding relevant lasting power of attorney if there is one for a person lacking capacity and
- in any case in consultation with those close to the person or with relevant knowledge of them, if the person consents to their involvement or if this involvement is in the best interests of a person lacking capacity.

Healthcare professionals should offer open and honest discussions with the person, considering their wishes, values, and medical condition. The decision should be made collaboratively, providing that this is consistent with the person's preferred approach, ensuring that the person and those close to them understand the implications.

Some people do not wish to engage in this open discussion and prefer to leave it to others, and this wish should be respected just as clearly as the need to be involved.

For other people it might be judged that to involve them in discussion of CPR would be harmful, in which case a decision might be made on clinical grounds. Any relevant knowledge of their values and preferences is still important even if they do not participate in the discussion.

In Northern Ireland, DNACPRs completed in the acute or hospice settings are not transferrable to community settings, and the person's condition must be assessed by their GP.

DNACPR decisions should be clearly documented in the person's medical records using standard and easily recognised documents, reflecting the rationale and discussions involved as well as the decision reached. Communication between healthcare professionals and relevant care settings is crucial to ensure the plan is clear during emergency situations.

DNACPRs are not legally binding, and do not override clinical judgement in immediately resolvable situations (such as choking or anaphylaxis).

DNACPRs may be temporarily suspended during anaesthetic for emergency surgery where the person may experience a reversible cardiac arrest, unless specified on an ADRT. However, DNACPRs may be more accessible and easily understood in an emergency as a record of a clinical intention.

For planned surgeries, discussions with the person or their attorney must take place beforehand to establish which interventions they would accept and refuse.

The approach should follow local (or in Wales, national) policy, and relevant guidance from professional regulators and bodies including that issued jointly by the Resuscitation Council UK, the British Medical Association and the Royal College of Nursing.

Power of attorney

In England and Wales, a power of attorney is a legal document that allows a person (known as the “donor”) to appoint someone they trust (known as the “attorney”) to make decisions on their behalf. The power of attorney comes into effect when the donor lacks the mental capacity to make decisions independently. It is important that the person seeks legal advice and fully understands the consequences of appointing an attorney.

There are two main types of power of attorney in England and Wales. Understanding the difference between these is crucial for people considering appointing an attorney to act on their behalf.

Lasting power of attorney (LPA) for health and welfare (England and Wales)

The LPA for health and welfare grants the attorney the authority to make decisions related to the donor’s personal welfare and healthcare when they lack the mental capacity to make such decisions themselves. This includes decisions about medical treatment, daily care, residential arrangements, and end of life care.

The appointed attorney is responsible for ensuring that the donor’s best interests and wishes are upheld and respected. An LPA is the only mechanism for someone to consent to treatment on behalf of an adult.

Attorneys for health and welfare can override existing ADRTs made before the power of attorney was granted, so the person must update or replace them to ensure these arrangements are in harmony with each other.

Lasting power of attorney (LPA) for property and financial affairs — England and Wales

The LPA for property and financial affairs grants the attorney the authority to manage the donor's financial matters and make decisions regarding their property and assets. This includes handling bank accounts, paying bills, managing investments, selling or buying property, and dealing with financial transactions on the donor's behalf. The appointed attorney has the legal responsibility to act in the best interests of the donor and manage their finances with care.

Each LPA must be registered with the Office of the Public Guardian before it can be used. Appointing a trusted attorney through LPAs can provide peace of mind and ensure that important decisions are made in accordance with the donor's wishes and best interests, even if they become unable to make those decisions themselves. An LPA ends when the donor dies.

Enduring power of attorney (EPA) - Northern Ireland

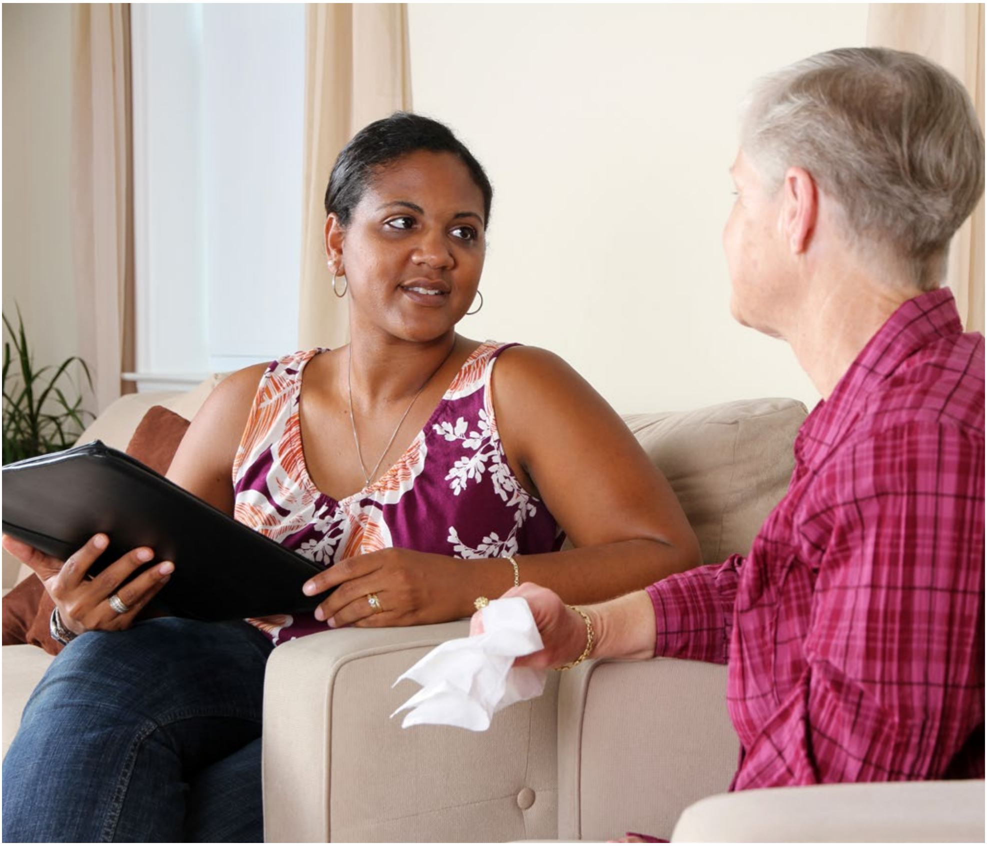
In Northern Ireland, the power of attorney system differs from that in England and Wales. Power of attorney in Northern Ireland only covers decisions related to property and financial matters, such as managing bank accounts, paying bills, and selling property — similar to the LPA for property and financial affairs described for England and Wales above.

An EPA takes effect as soon as the attorney signs the documents, unless the donor records that they cannot act until the donor loses the mental capacity to make decisions about their property and finances. An EPA ends when the donor dies.

Wills, trust funds and guardianship

A will allows instructions to be left about what will happen to money, property and possessions when someone dies. This is essential for ensuring wishes are carried out as expected, especially if there are problems within a family or where partners are not married.

Legal advice should be sought when making a will to ensure its validity. If there are concerns regarding guardianship of children, these will need to be clearly expressed. Some people may wish to set up trust funds to ensure the financial future of their family. The person should also be encouraged to gather important paperwork, such as information about bank accounts, and to keep these together with the will.



Organ and tissue donation

Donation for transplant is not usually possible after a person dies from MND, apart from the corneas. Research has indicated that there may be a risk of protein misfolding in the cells of people with MND transferring to the organ recipient. However, the NHS Blood and Transplant Authority agrees the organs of people with MND can be accepted for life-saving transplants if they die in hospital following an accident or from a cause unrelated to MND. See section 12 of the MND Association's End of life guide – see page 34.

Some people will want to donate brain and spinal cord tissue for MND research. It is not usually possible for someone to donate organs for both transplant and medical research.

If your patient wishes to explore brain and spinal tissue donation, in the first instance they should contact a tissue bank (also known as brain banks). Detailed information on tissue donation, and a list of tissue banks using tissue for MND research is available in Research information sheet I – Tissue donation. See page 39 for details of how to order a copy.

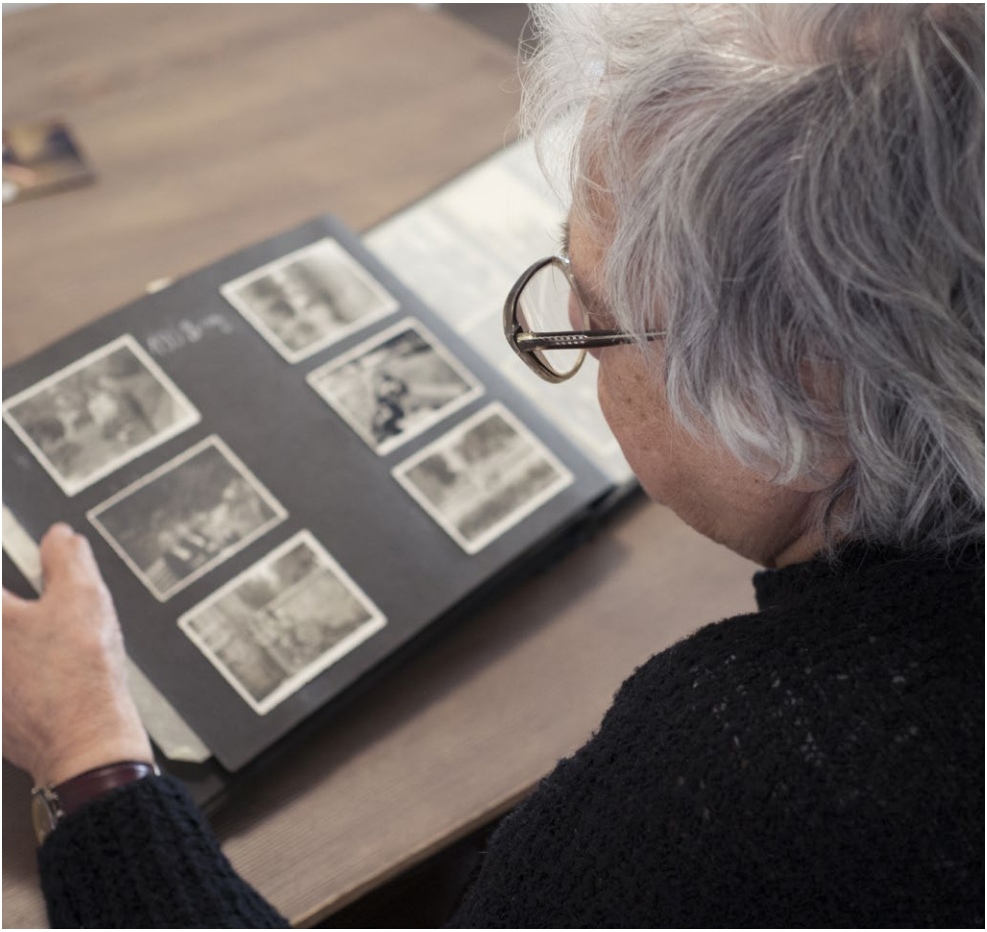
The decision should ideally be recorded in an advance care plan, and communicated with key members of the healthcare team, funeral directors and, where relevant, the tissue bank. If the person has registered to donate their tissue for research, their details will be registered with an individual tissue bank.

Any arrangements for organ or tissue donation should be made well in advance. The person should discuss with their family if they would like their organs or tissue to be donated once they have died. This is important, because even though the person's request to donate may be registered, the family will still be consulted at the time of death. Although they do not have the legal right to veto or overrule the person's decision to donate, there may be cases where it would be inappropriate to go ahead if it would cause distress to the family.

Funeral and memorial planning

By discussing wishes with their family, the person with MND can ensure a funeral or memorial will be as they would have wanted. For some people, this may include a direct cremation or burial, where no funeral service takes place.

Planning a funeral in advance saves the people left behind from worrying whether they've made the right choices. Some people choose to organise and pay for their funeral in advance. If religious rites or other rituals need to be observed, people may need to ensure arrangements are made before they die.



Planning for urgent situations

Professionals should work with people with MND and their families to identify potential emergency situations, such as respiratory distress, choking, infections, or sudden changes in health. Understanding the person's specific risks and symptoms is essential for proactive planning.

Establishing protocols and procedures for managing urgent situations is helpful. This includes clear guidelines for symptom management, hospital admissions, communication with healthcare providers, and involving palliative care teams for supportive care during crises. Not every crisis can be anticipated or planned for, so there is a need for flexibility when circumstances and preferences change unexpectedly.

Ensuring that the person has an up to date and easily accessible emergency contact list is vital. This should include the contact information of health and social care providers, hospice or palliative care services, and relevant family members or friends who the person may want to advocate on their behalf.

As most ACP documents are held by the person with MND, these should be stored so they are easily found in an emergency. The person's family and carers should be made aware of where these are stored. Paramedics and medical teams need to see these to be able to carry out the person's wishes. Some ambulance services may hold copies of ADRTs for people with limited life expectancy.

People with MND may find the following useful:

Message in a bottle: a sticker on the fridge and front door alerts healthcare professionals to a bottle in the fridge containing key personal and medical details. If forms do not fit, include a note of where they are stored. Bottles are free and usually available from local chemists. More information is available at: **lionsclubs.co**

MedicAlert: A registered charity providing an identification system for people with medical conditions and allergies, usually as a bracelet or necklet. These can include 'advance decision' to alert healthcare professionals to an ADRT. An electronic medical record and 24 hour helpline are also available. Find out more ar **medicalert.org.uk**

Digital Alerts: Mobile phone apps can display vital health information on the lock screen, such as emergency contacts or alerts like 'at risk with oxygen'. This allows responders to access key details even if the person is unconscious.

The MND Association provides the following tools, which may also be useful:

MND Alert Card: our small card the person can keep in their purse, wallet or pocket, to alert hospital staff that they have MND if they are admitted to a ward. It states that they need specialist help, and includes space to record key contacts. The card also gives a warning that the person may be at risk with oxygen.

MND Alert Wristband: our wristband that can be worn at all times if the person wishes. It alerts medical teams that they have MND if they are admitted to hospital. The band also gives a warning that they may be at risk with oxygen. A web address is printed to help professionals find information about urgent and emergency support for MND.

Understanding my needs: our form for the person to record basic notes about their needs. These notes say how they would like to be cared for if admitted to a hospital or a hospice, or if they have care workers at home. If the person has completed an advance care plan, they may not require Understanding my needs as well, but it has been designed with MND in mind and can help explain specific needs to care services.

See page 39 for details of how to order resources.

Recording and communicating decisions

It is crucial to accurately document all discussions, decisions, and preferences related to advance care planning. This documentation should be clear, comprehensive, and easily accessible to healthcare professionals across different care settings.

Family members need to be aware of the documents, and where to find them if needed. Advance care planning documents should be stored securely and made available when needed. Utilising electronic health record systems or shared care planning platforms can help ensure that the documents are readily accessible to healthcare providers.

Most ACP documents are patient-owned, and should be stored somewhere they can be easily accessed, with carers and family members being made aware of where to find these in an emergency – see Planning for urgent situations on page 30.

Communication with health and social care professionals

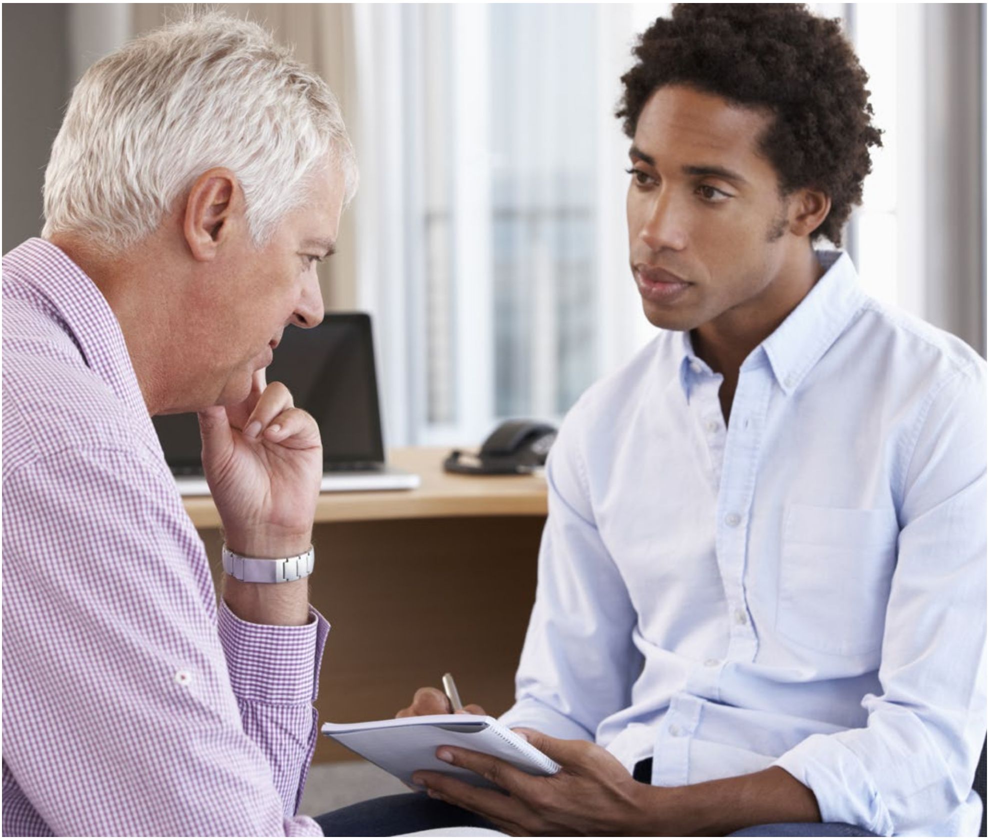
Effective communication between healthcare professionals, people with MND, and their families is essential for maintaining continuity of care. Clear and timely communication ensures that healthcare providers are aware of the person's preferences, treatment decisions, and care plans.

Conversations discussing wishes, preferences and plans for future care should also be registered and shared on national and local palliative care registers/ lists/co-ordination systems. Examples include the Gold Standards Framework, Electronic Palliative Care Co-ordination Systems (EPaCCS), Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) or eACP alerts in NHS Wales systems.

During transitions between care settings, such as hospital admissions or transfers to hospice or palliative care, effective communication is crucial. Providing comprehensive handover information and ensuring that advance care planning documents are shared with the receiving provider helps maintain consistency in care.

Review

Remember that the person's feelings and priorities can change over time. Advance care planning decisions should be regularly reviewed and updated regularly based on changes in the person's condition, preferences, or goals of care. The person should be made aware that they can change their ACP documents at any time.



Useful resources

MND Association's End of life guide, has been developed to help people with MND with end of life decisions.
mndassociation.org/eolguide

The Gold Standards Framework offers a range of resources, training and accreditation for professionals.
goldstandardsframework.org.uk

The Universal Principles of Advance Care Planning sets out six high level principles for advance care planning in England.
england.nhs.uk/publication/universal-principles-for-advance-care-planning

Advance Care Plan resource for England and Wales is a joint project from NHS Wales, the National Council of Palliative Care, Byw Nawr and Hospice UK. It has useful information for patients and professionals.
advancecareplan.org.uk

Resuscitation Council UK- ReSPECT website offers useful information on the ReSPECT process for both patients and professionals.
resus.org.uk/respect

Planning ahead - Hospice UK includes useful information for people considering advance care planning, and a tool to help people consider what is important to them.
advancecareplanning.org.uk/planning-ahead

Advance care planning: A quick guide for registered managers of care homes and home care services is a useful guide for registered managers, developed by the National Institute for Health and Care Excellence.
nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning

West Yorkshire Health and Care Partnership: Advance Care Planning and Bereavement Toolkit includes resources for people to have better conversations, support and personalised care about advance care planning and bereavement.
wypartnership.co.uk/our-priorities/long-term-conditions/palliative-care-and-end-life-support/advance-care-planning-and-bereavement-resources

How we can support you

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide information about our services mentioned below.
Email: mndconnect@mndassociation.org
Tel: 0808 802 6262

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for health and social care professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of support funds for people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on research for people with or affected by MND.
mndassociation.org/research

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We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to **education@mndassociation.org**.

If you would like to help us by reviewing future versions of our information resources, please email us at **education@mndassociation.org**.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call **0808 802 6262** or email **mndconnect@mndassociation.org**.

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**Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.**