

## 11: Planning ahead

**This section will help you to plan ahead for the later stages of MND.**

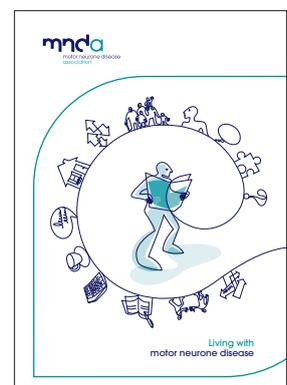
The following information is an extracted section from our full guide *Living with motor neurone disease*.

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

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)**



**Living with  
motor neurone disease**

# 11: Planning ahead



This section will help you to plan ahead for the later stages of MND.

The following includes information about end of life decision making. Read when you feel ready to do so.

“ I’m still in the early stages, but find qualified information helpful. It’s less frightening than looking on the internet.”

## Why has this section been included?

People with and affected by MND have told us they want more opportunities for sensitive discussions. This includes conversations about the later stages of the disease and end of life decisions.

“ When supported, you feel less daunted about what lies ahead.”

We aim to help by:

- training our own staff and volunteers
- providing relevant education opportunities for health and social care professionals
- providing clear information to enable you to have more effective discussions with professionals.

We provide detailed publications on symptoms, treatments and end of life decisions, so that you can find guidance when you need it.

See *Further information* at the end of this section.

“ I’ve always preferred to be told straight... I appreciate not everyone wants hard facts, but I think you have a duty not to shield us from the reality of MND.”

The following will highlight what to consider and why.

## Why would I need to plan ahead?

Discussions about late stage symptoms and end of life decisions can feel overwhelming. Some prefer not to think about this at all, while others prepare for the later stages of MND as soon as they can.

It can help to prepare as soon as you feel able to do so. This is because:

- speech and communication are likely to be affected as the disease progresses, making complex and difficult discussions more challenging
- fatigue with MND can make conversations very tiring
- some people also experience changes to the way they think with MND, making it harder to process information.

“ At first, when I couldn’t speak, I could still gesture with my hands and arms, so the difficulties were not as great.”

**“ Even with the best care in the world and maximum co-operation with your carer, the bigger problems of MND cannot be avoided.”**

Being prepared ensures your wishes can be fully considered. This can also ease worries, so you can focus on the things you really want to do.

**See Section 2: *Symptoms and management* and Section 8: *Speech and communication*.**

Most people have wishes they want to share about the end of their lives and are naturally concerned for those they love.

You may have wishes based on:

- personal preferences
- family needs
- cultural choices
- religious or spiritual beliefs.

These wishes may impact on:

- how medical treatment is provided and in what circumstances
- how your finances will be arranged and managed
- how legal arrangements are handled, eg Lasting Power of Attorney (or Enduring Power of Attorney in Northern Ireland) or your will
- guidance for your family and carer, to help them support you in the way you would prefer and to help support them in return.

**“ You worry about what will happen to your family after you’ve gone. It is therefore reassuring for everyone concerned to plan ahead and feel prepared for what is to come.”**

MND symptoms do progress. Although the speed of this can vary, it is sometimes rapid. You may find it gets harder to make and express choices, so it can be a good idea to think about what you might want in the future, as early as you feel ready to do this. For example, think about what you want to happen as your care needs increase. It can help to discuss this with your:

- family
- carer
- health and social care team
- legal adviser
- spiritual or religious representative, where needed.

Our MND Connect helpline can help if you find it difficult to know where to start. If you are in touch with one of our Association visitors, regional care development advisers (RCDAs) or a branch or group, they can also offer local information and support.

**See *Further information at the end of this section for contact details*.**

You may all find this hard at first, but having difficult conversations gives everyone a chance to share feelings. This can help you better understand how to support each other.

Children also have things they need to ask, say and do at this time. However, sensitive conversations can feel even more difficult with children and young people. There is a natural desire to protect children from distress, but they can sense tension and become insecure if not included. They may try to seek out information on their own or even blame themselves.

**“ We found a ‘post box’ useful for questions about the disease, as children and young people don’t always want a face to face discussion about the illness.”**

We provide publications to help you support children and young people. We also provide information on bereavement to support family members, friends and carers.

*See Further information at the end of this section and Section 5: Family, children and friends.*

**“ As soon as I got the children’s resources, I read through them. It was a bit like, you know, when you give your daughters or sons the book of life and think ‘I will just check this out first’. I read it front to back and it answered so many questions... probably every question that I’d never thought of was in this book, in such a way that it wasn’t as scary as I’d thought...this was reassuring even though honest. That’s what you want. We wanted honesty – how is it going to be? What do we do if this happens...?”**

## **Palliative and hospice care**

Many people with a life-shortening illness are fearful of receiving palliative or hospice care. It raises the question, ‘Does this mean I’m at the end of my life?’. However, this is not necessarily true.

Palliative care is very much concerned with quality of life, from the point of diagnosis onwards. It is designed to help you receive the best possible medical, practical and emotional support, according to your wishes. The earlier you can access this care, the more benefit it can bring.

If hospice services are limited in your area, palliative care teams can also be accessed through hospitals and clinics.

**“ I’ve been to a hospice for MND support meetings, which made me quickly realise a hospice offers much more than a place to die. But when the time comes I also feel it will be handled with so much dignity that it banishes fear about the end.”**

Depending on your needs, you can receive palliative care at home, in hospital, in a nursing care home or at a hospice.

Where available, palliative care can be particularly beneficial for people with MND. As the disease progresses and care needs become more complex, much can be done to relieve symptoms and provide guidance. This does not necessarily mean admittance to a hospice or hospital.

Palliative care also extends to immediate family. For example, once the person with MND has been referred, counselling may be available for the whole family.

We advise asking your GP if you can be referred to a palliative care team as soon as you have been diagnosed. If you have a slower progressing type of MND, this may not be necessary yet, but try to get as much information as possible.

There may be a waiting list, but it is better to be on the list than asking for referral at point of need. The knowledge a palliative care team or hospice can build about the individual may also help to reduce time in hospital if urgent or emergency treatment is required.

**“ At the hospice, it’s reassuring to meet with staff who seem to have more time to build a rapport.”**

## What else do I need to consider?

Planning ahead can be complicated. Your specific symptoms, personal circumstances and beliefs will all influence your wishes. Over time, you may change your mind about the choices you make, but you can review and amend any plans you put in place.

“ There is a sense of relief it’s all in place and not something still to be tackled.”

Ensuring your wishes and preferences are known can help to reduce anxiety. Keep all important documents safe, but easy to access when needed. Provide up to date copies to those involved in your care, as appropriate. This may include sharing passwords to computer files with your family.

When you feel ready, we recommend exploring the following in more detail, so that you can make informed and timely decisions.

**See Further Information at the end of this section for resources with more detail.**

**Late stage symptoms:** as your needs become more complex, your health and social care team will be able to advise. Options such as assisted ventilation to help with breathing, or tube feeding to support eating and drinking can be discussed. Ask for guidance as soon as you begin to experience any symptoms, as some interventions may be difficult to introduce in later stages. You may also want to discuss what will happen if you wish to have treatments withdrawn in the future.

**MND Just in Case Kit:** a box containing medication prescribed by your GP, that you keep at home for emergency use. This can help with breathlessness and anxiety, and having the box at hand can be reassuring.

Your GP can request the kit, free of charge, from the MND Association. There is a section with medication that visiting health professionals can use. There is also a section with medication and instructions that a carer can use, as explained by the GP, or a community or district nurse.

**Advance Care Plan:** a document in which you record preferences about your care in case you become unable to make your wishes known. It is not a legal document, but health teams will take note of your choices. These could include where you wish your care to take place, how you would like care provided, or aspects of your faith or beliefs. You can’t use it to insist on a treatment that isn’t right for you, but it can say what things you’d accept in the future, as well as those you’d prefer to avoid. Making people aware of wishes can be important if gets more difficult to explain, and you can change the wording at any time.

“ I hated fussiness. Now I’m the most finicky fusspot you could imagine – or so it must seem to anyone who makes my bed or prepares my food.”

**Advance Decision to Refuse Treatment (ADRT):** a document that lists any treatments you do not wish to receive and in what circumstances. When completed correctly and witnessed, an ADRT is legally binding in England and Wales, but not in Northern Ireland or Scotland (although it must still be taken into account by the health and social care team and anyone making decisions on your behalf). It only becomes valid if you lose the ability to make or communicate decisions for yourself. It is important to create an ADRT with your doctor or health team, so that you have a full understanding of your options and the implications. Such decisions also need to be communicated to all appropriate members of your care team and family.



“ If my husband had left instructions in an ADRT, we wouldn't have undergone the stress that we did.”

An ADRT cannot be used to request any form of treatment to deliberately hasten death, but it can include the right to refuse life-sustaining treatment. You can review and change your ADRT at any time.

**A will:** a legally binding document where you state what will happen to your possessions and money after your death. If you die without a will (known as dying intestate), your possessions will be distributed amongst members of your family as defined by law, which may not be what you want. This can make it difficult for loved ones to manage your estate - more so if not legally related to you. For example, cohabiting partners will not have the same legal standing as a spouse.

**Power of Attorney:** a legal document to let someone you trust make decisions, if you become unable to communicate or make decisions for yourself (known as lacking mental capacity).

In England and Wales this is called a Lasting Power of Attorney (LPA), which is registered with the Office of the Public Guardian (OPG). You will be charged a fee. There are two types of LPA:

- for property and finance (which can also be used by the appointed person if you still have capacity, should you agree)
- for health and personal welfare, where the appointed person makes decisions on your behalf if you lack capacity. This can invalidate any previous ADRT.

In Northern Ireland this is called an Enduring Power of Attorney (EPA), which is registered through the Office of Care and Protection. An EPA only enables decisions on your behalf concerning property and finance, not personal welfare or care related matters.

### **NHS continuing healthcare (CHC):**

describes a package of health and social care, arranged and fully funded by the NHS to meet complex health needs. The primary need must be for healthcare, following assessment to see if you qualify. CHC works in a similar way in England and Wales. In Northern Ireland there is no guidance on CHC, but health and social care trusts are encouraged to refer to the criteria used in the rest of the UK.

### **Where you wish to receive care and preferred place of death:**

where you wish to receive care and your preferred place of death should be respected. It may not always be possible to ensure your wishes are carried out, as this depends on circumstances and your health needs. However, it is easier to make arrangements if planned ahead of time. Location choices include a nursing care home, a hospice, a hospital or remaining at home. It is really important that the person with MND, their family, carer and health team are all involved in discussions. Such decisions often change with time and should be regularly reviewed.

**Funeral arrangements:** you may want your funeral arranged in a specific way. If so, it can be helpful to leave instructions for those close to you or to discuss your wishes with them. This may involve messages, chosen words or music, or things you would like included because of belief or faith. If you are concerned about the cost, a pre-paid plan might be possible, or the person arranging the funeral may be entitled to a benefit payment to help with this. A funeral director will be able to provide guidance about arrangements.

**Organ and tissue donation:** if you are interested in organ or tissue donation, we recommend exploring possible arrangements for this at the earliest opportunity. This can be more complex to arrange with MND, but we provide information to help.

**See Further information at the end of this section.**

## MND alerts

If you become unable to communicate for any reason, a range of tools can help alert hospital staff and care workers that you have MND. These can be used in urgent or emergency situations, or for general care. These alerts are important, as not all health and social care professionals are experienced with MND.

### Our alerts

Our own alerts are MND specific and most warn that you may be at risk with oxygen. Prolonged use of oxygen with MND can upset the balance of gases in your blood. It may still be used in certain circumstances if your levels are low, but with caution and monitoring.

**MND alert card:** our small card for you to carry in a purse, wallet or pocket (this includes the oxygen alert). It tells professionals that you need specialist help and has space for you to record key contacts.

**MND alert wristband:** this has a similar purpose to the MND alert card (including the oxygen alert), but can be worn all the time. It states that you have MND, with a web page address for professionals about urgent MND care.

**Understanding my needs:** our write-on booklet to help you record your needs and personal background (this includes the oxygen alert). Once completed, keep this with you to help inform anyone involved in your treatment or care.

**MND checklist:** our form to alert you on what to think about, when first diagnosed. This may help you better manage your condition and arrange for appropriate support.

Our alert card, wristband and Understanding my needs booklet are all included in the folder with this guide. All of our resources can also be ordered through our MND Connect helpline.

**See Further information at the end of this section for details.**

**Message in a bottle:** a sticker on your fridge and the inside of your front door tells paramedics that an alert bottle can be found in the fridge. You can use this to store essential personal and medical details. The bottle is not large enough to hold items such as an ADRT, but you could add a note about where to find such documents. Bottles are free of charge from your local chemist. You can also contact the Lions Club for details – see their contact page at:

**<http://lionsclubs.co>**

**MedicAlert:** this registered charity provides an identification system for individuals with medical conditions or allergies. Usually 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)**

**Carer emergency card:** a card that carers can carry in case they are involved in an emergency and unable to communicate. Usually linked to a registration service, the card alerts authorities, so you can be supported if your carer is unable to help. Ask your local authority in England or Wales if they have a carer card scheme. Ask your local health and social care trust in Northern Ireland about emergency and out of hours care support.

**Telecare and telehealth:** enables you to use an automated alarm system through a telephone line. These systems can help if you have a fall or need urgent assistance. Ask your GP or adult social care services about how to access equipment. There may be a charge for this service.

**Texting emergency calls to 999:** you can download an app for the NGT service, which enables text calls to emergency services through 999. See more information at **[www.ngts.org.uk/how-to-use-ngt/contact-999-using-ngt.html](http://www.ngts.org.uk/how-to-use-ngt/contact-999-using-ngt.html)**

## Key points

- If you begin to have problems with speech and communication, try to get your wishes for future care written down in an advance care plan or ADRT. You may also wish to get your affairs in order, such as making a will. The later you leave these arrangements, the harder it may be to have detailed conversations.
- Keep copies of important documents like your ADRT in a safe place, but easy to access when needed. Ensure someone you trust knows passwords for access to computer files, where appropriate.
- Your views may change over time, in surprising ways. Don't worry about expressing this. You have the right to change instructions, and for your views and wishes to be respected.

## Further information:

### From our range of information sheets:

- 1A: *Nice guideline on MND*
- 4A: *Communicating about MND with children and young people*
- 6C: *Managing pain*
- 7A: *Swallowing difficulties*
- 7B: *Tube feeding*
- 7C: *Speech and communication support*
- 8A to 8D:  
*our range of sheets on breathing and ventilation support for MND, including withdrawal of ventilation*
- 10D: *NHS continuing healthcare*
- 11C: *Equipment and wheelchairs*
- 14A: *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

### From our guides and other publications:

***End of life – a guide for people with motor neurone disease:*** our comprehensive guide to end of life discussions, advance decisions, future care, getting affairs in order, organ and tissue donation, wills and other planning.

***Understanding my needs:*** a booklet in which you record your needs and preferences to guide all those involved in your care.

***MND checklist:*** our form to help you think about support planning when first diagnosed.

***What you should expect from your care:*** our pocket guide on questions to ask at appointments, based on the NICE guideline.

***Caring and MND: support for you:*** a comprehensive guide for carers.

***Finding your way with bereavement:*** our guide to help with grieving when someone dies, including anticipatory grief before death.

***When someone close has MND:*** a workbook for children aged 4 to 10 to help a trusted adult communicate with them about MND.

***So what is MND, anyway?:*** a publication about MND and its impact for young people and young carers up to the age of 18.

***Research information sheet I: Tissue donation:*** explains how donated tissue may be used and how to go about arranging for donation.

### Information to pass to your health or social care professionals:

***P4A: MND Just in Case Kit (introductory sheet)***

***P11: Pain in MND***

***A professional's guide to end of life care in motor neurone disease***

***MND in acute, urgent and emergency care***

***Supporting children and young people close to someone with MND***

Download our publications at:  
**www.mndassociation.org/publications**  
Or order them from **MND Connect**, our  
support and information helpline:  
Telephone: **0808 802 6262**  
Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external  
services and providers, and introduce  
you to our services, where available in  
your area, including your local branch,  
group, Association visitor or regional care  
development adviser (RCDA).

**See Section 12: How we can help you.**

#### **Online forum:**

A safe place to share information and  
support with others affected by MND at:  
**http://forum.mndassociation.org**

#### **Samaritans:**

A listening service for confidential support.  
**www.samaritans.org**  
Telephone: **116 123**

#### **Office of the Public Guardian:**

Search for lasting power of attorney at  
**www.gov.uk** for information about power of  
attorney in England and Wales.  
Telephone: **0300 456 0300**  
or textphone: **0115 934 2778**

#### **Office of Care and Protection:**

Search for EPA at: **www.courtsni.gov.uk**  
for information about Enduring Power of  
Attorney in Northern Ireland.  
Telephone: **0300 200 7812**

#### **Government online information:**

For advice about benefits and other matters,  
such as NHS continuing healthcare.  
**www.gov.uk** in England and Wales  
**www.nidirect.gov.uk** in Northern Ireland.

#### **Record Me Now**

A downloadable free app to leave video  
messages for your family and children at:  
**www.recordmenow.org**

#### **Digital Legacy Association**

Online help about what to do with any online  
records that may be left in your name at:  
**https://digitallegacyassociation.org/  
for-the-public**

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For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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

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



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