



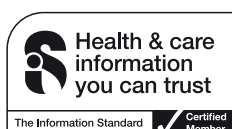
A guide for people with

MIND

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The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

What do professionals say about this guide?

"I think this booklet tackles end of life issues in MND with great courage and sensitivity. As a palliative care nurse I found this information very useful to apply in my practice."

Debi Adams, Clinical Nurse Specialist in Palliative Neurology, Saint Catherine's Hospice, Scarborough.

"This is an important and potentially landmark piece of writing. Lots of real gems and very much in a style which I find works in face to face contact with people. I have faith that the MND Association is doing the right thing in making this material available."

Dr Colin Campbell, retired Palliative Medicine Consultant, Saint Catherine's Hospice, Scarborough.

"A well-written and thoughtful guide which covers some really difficult and sensitive issues. It looks clear and I particularly like the use of example questions for how to start conversations and the practical level of advice."

Amanda Mobley, Clinical Psychologist, Community Neuro-Rehabilitation/Stroke, Walsall Healthcare NHS Trust.

"This publication will encourage end of life discussions between people with MND and their family and with health and social care professionals. They may be difficult conversations but they are so important, as they allow the person with MND and their family to ensure that their own wishes are known and the appropriate care and support can be provided."

Dr David Oliver, retired Consultant in Palliative Medicine, formerly at the Wisdom Hospice, Rochester and Honorary Professor, Tizard Centre, University of Kent, Canterbury.

"Congratulations on the project – it will be valuable both for people with MND and their families."

Dr Nigel Sykes, Consultant in Palliative Medicine and Medical Director, St Christopher's Hospice, London.

What do people living with or affected by MND say about this guide?

"A very comprehensive guide which will be really helpful. I do hope that health professionals have time to read or at least refer to it. Excellent."

"Thank you for having the courage to tackle this. I found the references to end of life options an essential part of the guide and, believe it or not, very refreshing."

"Very simply put and easy to digest."

"I found this extremely helpful. Especially as a springboard for further discussion with professionals."

"We've got to talk about how people with MND come to the end of their lives and acknowledge the support available, otherwise the end of life stage is a very lonely and frightening place. I'm so pleased that it has entered the conversation."

"A very difficult subject to cover, but has made me realise that my husband and I have to discuss end of life options for treatment and withdrawal of treatment more fully."

"By reading about it, you are more familiar with the subject and better informed, and therefore more confident to take discussion forward with others."

"Having full information available is essential, if you don't want to read it you don't have to."

"There is a sense of relief that all the guidance is accessible in one document and covers everything we need to know."

Foreword

Many of us resist exploring or talking about end of life decisions until we have to. We often avoid these conversations, as they may feel uncomfortable or upsetting. Yet the need for relevant information on end of life can become very important if you, or someone close to you, receives a diagnosis of motor neurone disease (MND).



This can be devastating news and you will probably need time to adjust, but there is usually a point where you want to plan ahead.

Our members frequently tell us they would like better information about end of life decision making. Many are seeking full, clear and honest answers to their questions, to assist with decision making about care, treatment, finances and family. Until now, people have had to search for this guidance in various places.

In response, we have developed this groundbreaking publication, *End of life: a guide for people with motor neurone disease*. It pulls together end of life information in one place, with clear directions about who to ask for further detail.

The aim of this guide is to help make these sensitive and important conversations easier, in the hope that more people with MND will be able to achieve a dignified death, where their wishes are acknowledged and respected.

The content is candid and comprehensive, making this guide the only one of its kind for people with MND in the UK. Knowing the facts can remove a great deal of fear and can help you begin to take back control in a situation that can often feel overwhelming.

You may wish to read the guide in stages or use it to find answers to specific queries, perhaps with the support of those close to you or a member of your health and social care team.

MND can progress rapidly and affect speech and communication. Try to discuss your future needs and wishes as early as you can. The guide provides helpful suggestions on how to begin conversations with family, friends, children and health and social care professionals.

Many people tell us they feel relieved after making their end of life decisions. We hope this guide will help to ease this process so that you can get on with living.

Thank you to everyone who has contributed to this guide, from our members who have shared their personal experiences to our expert panel. You have all helped to make a real difference for others living with or affected by MND.

Sally Light

Chief Executive
MND Association

How to use this guide

Whether you are living with motor neurone disease (MND) or close to someone who has been diagnosed, end of life concerns can create confusion and fear. This guide explains the terms used within end of life care and the options available, to help you consider your needs, preferences and wishes.

What does the guide contain?

If you have requested this *End of life guide*, you are probably looking for answers to difficult questions. If you are ready to ask these questions, we believe you should receive honest and open information in return.

The content of this guide is comprehensive and covers a wide span of concerns raised by people affected by MND through interviews, surveys and feedback.

Studies and findings have shown that when people are empowered about end of life decisions, it helps them seek out and receive the best possible care.

See Section 14: *What people with MND have said about end of life.*

We have tried to provide this information with sensitivity, but also transparency. Please be aware that we will refer to death and dying, as the subject matter deals with end of life, but each section is clearly introduced so that you know what to expect.

The guide provides information about:

- medical treatments and what can be done if a time comes when they are no longer helping
- how to broach sensitive subjects with family, friends and health and social care professionals

- how to gain the best possible benefit from available support systems
- ways to communicate and gain respect for your wishes, preferences and needs.

We hope to enable more people with MND, wherever they live, to access specialist palliative and end of life care. Part of our work towards this is to provide better information about the options and services available at end of life. We hope this guide will help more people with MND, their families and carers, to feel informed and empowered to better navigate and manage their care.

Should carers read this guide too?

It is important that end of life decisions are discussed with those close to you, so that they know your wishes and preferences. We recommend sharing this guide with your main carer. They can support you while you gather information about end of life decisions. They can also help to ensure your wishes are respected.

See Section 7: *Discussions with family and children.*

Do I need to read it all?

You don't have to read the entire guide in one sitting. Read as much as you wish and return to the guide when needed, for further information.

The guide is split into numbered sections to make them easy to find. These sections are grouped into five main parts. Each part is colour coded to help you find it easily:

Part 1: What do I need to think about?

Part 2: What is likely to happen?

Part 3: What do those close to me need to know?

Part 4: What else might I need to know?

Part 5: How do I get further help?

We have also included the following features to assist you:

- **key points:** to highlight things you may need to consider
- **further information:** listed at the end of each main part of the guide to help you order or download additional information appropriate to the subject matter

Are the quotations all from people affected by MND?

We have included a few quotes from health and social care professionals, which are attributed. However, the majority of quotes are anonymous, from shared personal experiences of MND. These are all from people living with or affected by MND, as gathered from feedback, surveys and studies.

See also Section 14: What people with MND have said about end of life.

Further support

In the final part of the guide, *How do I get further help?* we have explained how we can support you or direct you to specialist services.

If you have any specific questions about anything in this guide or any aspect of living with the disease, please contact our helpline.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

Website: www.mndassociation.org

MND Association

PO Box 246

Northampton NN1 2PR

If you live in England, Wales or Northern Ireland

While the MND Association is keen to help everybody affected by MND, our charity specifically supports those living in England, Wales and Northern Ireland. We endeavour to ensure our information is relevant to all three and to indicate major differences between their health and social care systems. However, as the NHS and government structures work in slightly different ways, the terminology and processes they use can vary. Always check with your local service providers for guidance on specific types of support.

If you live in Scotland

If you live in Scotland please contact MND Scotland for advice on specific support and services.

See Section 16: Useful organisations for contact details.



What do I need to think about?

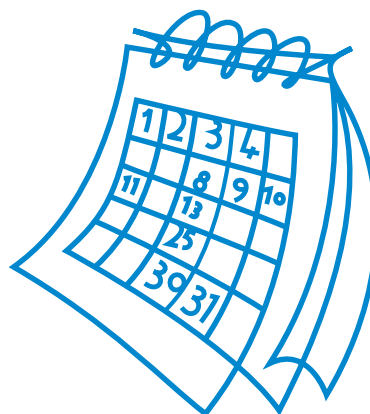
Section 1: Why plan ahead?

Section 2: Emotional and psychological support

Section 3: Difficult conversations with professionals

1: Why plan ahead?

This section explains why it is beneficial to plan ahead for end of life.



“Coping after such a devastating diagnosis is always a challenge – but help is available. With the right care and support, many people have told us they can maintain their quality of life and find ways to manage day-to-day tasks. Even the later stages of what is ultimately a fatal disease can be met with dignity and a sense of control, when the right support is there.”

Sally Light, CEO at the MND Association

By choosing to read this guide, you have decided to explore what end of life may mean for you. By researching your options, you begin to take control of how your end of life decisions can be managed.

Most people tend to avoid talking about end of life. This is natural, as our instinct to survive is strong and we focus on living and looking forward.

“ I didn’t think about end of life before I had MND. You just don’t.”

When your future is threatened, it can leave you feeling devastated. Your dreams and goals are suddenly in question and your routines and plans have to be reassessed. A period of shock usually follows diagnosis, which extends to family and friends too. You may even feel a sense of denial when told you have a life-shortening disease. This can seem unreal or you may hope that the diagnosis is wrong.

“ We all have to face fear of death at certain points in our life and serious illness brings this to the fore. From our experience, it is better to be in a position where you feel as prepared as you can be.”

Fear of death is often linked to 'not knowing' what is ahead. This can be made worse by reports you may hear, which are not always based on fact. You may find your fears easier to deal with by finding out about end of life care and the options available. This guide will help you start gathering information.

How will planning ahead help me?

Planning ahead makes it more likely that you will receive the care you want, rather than relying on services being available at short notice. Most people find that making plans can be reassuring, enabling choice and control over what happens in the future, as far as is possible.

“ Once you’ve done it, you can put it away in a cupboard. You can relax...and you feel better for doing it.”

It’s important to remember that:

- thinking about end of life does not bring it closer
- you have the right to change your mind and change your plans at any time

- once you have made your plans you can get on with living
- many people find that planning ahead brings peace of mind.

Let your loved ones know about the decisions you make and have regular discussions, as your views may change. It can be a huge relief for those close to you to be made aware of your choices, so they can try to respect your wishes.

If your speech and communication are affected, try to have difficult conversations as early as possible, so you can discuss sensitive and complex issues more easily. If you feel tired or emotional doing this, you can tackle it in stages.

“ My approach is to be open and frank and then move on. The problem is that, as a society, there is a huge taboo about dying.”

Whatever decisions you make, it is important to recognise that the health and social care team, including local palliative care services, can support you and your family, and help to ease your symptoms and worries.

See later heading in this section, *Are end of life care and palliative care the same?*

What type of plans should I be making?

Planning ahead is about being prepared. This usually includes:

- getting your financial and legal affairs in order, such as writing a will and ensuring those close to you are aware of important records
- asking your health and social care team about treatment options, so that you can make decisions about these at the right time
- considering future housing or nursing care options in case your care needs become complex

- caring for children and planning for their future
- ensuring your preferences about your care are written down, in case you become unable to express them in the future
- having open discussions with your family carer, relatives and friends so that everyone is aware of your choices
- identifying who would make decisions on your behalf should you become unable to do so yourself
- deciding on your preferred place of care and death
- being prepared for emergencies
- deciding on funeral arrangements, if you have wishes you would like to be respected.

See Section 7: *Discussions with family and children* and Section 8: *Putting affairs in order.*

You may want to explore your spiritual or religious beliefs or have practical questions about dying: ‘What is likely to happen to me?’ and ‘How will I die?’ are frequently asked questions.

See Section 2: *Emotional and psychological support* and Section 5: *How will I die?*

Be prepared that not everyone will necessarily like your choices about end of life, which can be challenging, but open discussions may help. Others may not understand why you are making certain choices, so explanation is useful. You may find these conversations easier with a member of your health and social care team present.

“ We’re born and we’re all going to die. Dying is as important as being born.”

When is it best to start talking about end of life?

Discussions about end of life 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.

“ I was in denial at the beginning, but as soon as you can come to terms with it, you can have a better quality of life for the rest of your life ... Now everything is an opportunity to live life.”

Because the progression of MND is unpredictable and sometimes rapid, your health and social care team may introduce end of life discussions before you feel ready.

“ The neurologist jumped in feet first and said, ‘If I were you I’d go and sort your will out and do a lot of travelling.’ This knocked my husband sideways.”

If you are asked to think about end of life shortly after diagnosis, you may worry that you are already in the later stages of MND. However, there are good reasons why early discussion may be encouraged, as:

- speech and communication can be affected by MND, making it tiring and more difficult to have detailed discussions as the disease progresses
- cognitive impairment (changes to thinking and reasoning) can also occur for some people with MND
- you may want to consider who you would like to act on your behalf, should you become unable to communicate or make decisions.

See Section 9: Advance care planning and advance decisions.

Opening the conversation is the first step, but you don’t have to plan everything at once. Some decisions, such as options for treatment, may only be necessary if you begin to get certain symptoms. However, finding out about these as early as you can, means you are prepared to make timely choices, if needed.

“ Issues don’t always come out in the first conversation. This needs time to evolve and for relationships to build. People need time to think things over.”

What if I have a slower progressing type of MND?

If your MND symptoms are progressing slowly, you may feel you can wait longer before making end of life decisions. Your circumstances and outlook might change and there may be less urgency.

“ We haven’t yet had that conversation, as he’s still quite good. The time comes when it’s right, and it’s obvious that the conversation will need to happen.”

However, a slower progressing form of MND can develop into a faster form, so there is still an advantage in considering what your plans might be.

Ask your neurological consultant if you are unsure about the speed of your progression and which type of MND you have, although this is not always easy to determine.

How do I plan ahead?

Gather as much information as you can from your health and social care team. Although having these conversations early is valuable, try not to rush major decisions. You may find your views adjust as you find out more detail.

Once you know what can be done and have thought about what you would prefer, you can tell others about your wishes and leave written instructions to help guide them.

“ Family and friends don't necessarily understand or have a full picture of all the issues.”

The more informed you are, the easier it will be to explain to others how you would like your future care to happen.

“ I wanted to know everything.”

You can plan ahead by:

- making decisions about future treatments, such as tube feeding or help with your breathing
- determining the best timing to introduce treatments, with further help from your health and social care professionals
- creating an advance care plan in which you leave written instructions about your medical and social care
- clearly recording any Advance Decisions to Refuse Treatment (ADRT) that are important to you
- thinking about contingency planning to ensure you, your main carer and your family know what to do in unexpected situations
- investigating how to get help with care at short notice, should your main carer be unable to support you at any time

- nominating someone you trust to make healthcare or financial decisions on your behalf, through a Lasting Power of Attorney (LPA) in England or Wales. Enduring Power of Attorney (EPA) provides a similar function in Northern Ireland
- ensuring those close to you know what your wishes are and where any related documents or forms are kept.

See the following sections for more detail:
4: What to expect as the disease progresses.
6: What care is available?
9: Advance care planning and advance decisions.

In most cases, you can change your instructions at any time, but be careful when making financial decisions, which you may not be able to reverse. Talk to a solicitor, an independent financial adviser or a benefits adviser if you are in any doubt.

Are end of life care and palliative care the same?

When making decisions about end of life, you will often hear the terms palliative care and end of life care. As a result, these terms are used throughout this guide and it is important to understand the difference, as they can be confused.

Palliative care:

When you have a serious and potentially life shortening illness, additional support beyond any immediate primary health care is known as palliative care. Depending on your circumstances, this may be provided from the point of diagnosis onwards.

It is provided for people with MND by primary care teams (for example, your GP and community nurses), health and social care professionals at neurological clinics or MND Care Centres and Networks, and also by specialist palliative care services (whether in your home, a hospital, hospice or day centre).

Whatever mix of services is available in your area, they all work together and their focus is on helping you to achieve the best possible

quality of life, with access to a wide range of health and social care support. This can include symptom control and support for any psychological, social, spiritual, religious or other needs. This support also extends to your family and carers.

[See section 6: What care is available?](#)

End of life care:

End of life care concentrates on identifying your needs, and those of your family and carers, during the last phase of life and into bereavement. This usually means the final 12 months and includes palliative services. The primary focus is to support the needs, preferences and wishes of the person approaching death, to help them live as well as possible until they die, and to die with dignity.

Key points

- Discussing end of life does not bring it closer, but at some point you will probably want to make decisions about your future care. If this is planned and communicated, there is more likelihood that your wishes will be understood and respected.
- The progression of MND can be rapid, but talking about your wishes helps you to plan ahead and give your loved ones personal goodbyes.
- It can be a relief for those close to you to have your wishes about your future care written down. If you become unable to communicate for any reason, it can help them to feel more confident and take away the responsibility of having to make those choices for you.
- It is better to plan ahead, rather than leave everything to chance. If you are in any doubt about a choice you have made, even in a legal document, this can be amended.
- Even if you feel unsure about what you may want, it is still useful to discuss and write down general preferences about your future care. This may not be specific, but it can still help to guide others involved in your care if decisions need to be made on your behalf.

2: Emotional and psychological support

This section looks at the emotional and psychological impact of thinking about end of life decisions.



What should I prepare for emotionally?

Thinking about end of life is rarely an easy task. Some of the decisions you will face are likely to feel uncomfortable, yet everyone's experience will be different.

“ The basic truth is that anyone in my position or similar will have fears, but not all the fears will be the same...Everyone will be worried about something, so it's a case of trying to get that person to be comfortable, and to talk to them about their fears.”

Thoughts may persistently trouble you, such as:

‘What will happen?’

‘Will it be frightening for me and those who care about me?’

‘Will it hurt?’

‘Will I lose control?’

‘Will it be dignified?’

‘What impact will this have for my family and friends?’

All of these questions, and many more, may affect how you feel. Yet many people report that they feel relieved and much calmer having made their plans and knowing what is likely and less likely to happen.

“ I've been lucky. I had a very supportive team who I could discuss advance decisions with, but even this was hard emotionally. Now that I've done it I feel better.”

It is normal to expect heightened emotions when facing end of life decisions. It is a particularly sensitive time and every individual will have a different set of circumstances, needs and preferences. Your feelings will be personal to you, but influenced by those around you. You can experience more than one distinct feeling at a time, such as anger, guilt, sadness and a sense of relief.

You may experience some or all of the following:

- a sense of being overwhelmed, as end of life decisions can be complex
- fear for the future and what may happen to you
- anxiety for family, children and friends
- a sense of loss of control over your life and what will happen to you
- feelings of panic
- anger at the medical profession or family and friends, if they seem to be arranging things in a way that doesn't meet your wishes
- isolation, if you feel a sense of separation from others who are not in your position
- intense sadness for your own loss and for your family
- guilt that you may be the cause of stress for others

- tension with those close to you, as this may be stressful and tiring for all of you
- an intense closeness with those you love, as bonds can become tighter
- relief that you finally know what options are available to you and can express your wishes
- a feeling of resignation or acceptance.

These are all normal and expected reactions to challenging circumstances. With support from health and social care professionals, and those close to you, difficult feelings usually become more manageable over time.

Anticipatory grief

You, your partner, main carer, relations and friends will all be facing emotional upheaval during this time. There will be pressure to discuss sensitive issues that might feel upsetting. You may all experience what is known as 'anticipatory grief', where you begin to grieve for the loss to come and feel a sense of impending dread.

" You grieve on diagnosis. I was inconsolable for about a month, but then it got much better."

There will be grief for losses along the way too. The progressive nature of MND means that physical independence, expression, communication and activity may all be affected. This can sometimes be rapid. Not only are you likely to feel grief about dying, but about each limitation that MND may bring.

" He experienced increasing distress and frustration because of his symptoms, which were affecting his life and work significantly. It was distressing not only for him, but for all the family."

Talking openly to those around you can help to reduce some of the anxiety that anticipatory grief can cause.

See later headings in this section, *What can I do to help manage my emotions?* and *Who else can I talk to?*

This is important for everyone involved, as the grieving process can affect all those in your close circle. If you have a main carer who provides ongoing support, it can be intense for them, as they will be particularly aware of the disease progression. They will also find their relationship with you changing in order to meet the challenges of the caring role.

" Carers are just as important as the patient and their fears are for themselves as much as the person they are caring for. They need their own support."

See section 7, *Discussions with family and children*. Also *Further information* at the end of Part 1: *What do I need to think about?* where we provide details about our publications for family carers.

What can I do to help manage my emotions?

You will probably discover various ways to cope with emotional overload. If you find it difficult to show your feelings, try to allow yourself to express anger, irritation, tears – even laughter, as these can all help release tension.

It is okay to feel emotional about what is happening, but try to talk this through with those close to you and give them permission to do the same. You may even find this brings you closer. Without open communication, emotional tension can build and make it more difficult to tackle what lies ahead.

Often, it is the sense of losing independence and control to the disease that takes its toll. Many people with MND have said that taking positive action can help you feel more in command. This can help rebuild confidence, reduce frustration and lift you from sadness.

People living with MND have found the following helpful:

- doing something physical, like gardening, with assistive equipment to help you stay active for as long as possible
- planning a trip, event or holiday (many travel providers provide accommodation adapted for people with disabilities)
- seeking out experiences with family and friends that will provide lasting memories
- using speech and communication aids to help you maintain communication and social contact should your ability to speak and gesture be affected
- listening to music or going to music therapy sessions
- having physiotherapy, with a qualified physiotherapist who has experience of MND
- having hydrotherapy, where exercise is assisted and supported in water to help you move and flex joints safely
- trying one of the many complementary therapies with a qualified and registered practitioner (if wished, family members may be able to learn helpful massage techniques to provide help at home).

See Further information at the end of Part 1: *What do I need to think about? for a list of publications with details about therapies, equipment and ways to prolong your independence.*

“ The thing about MND is that the goal posts are constantly moving... But you just have to adapt as you change. It’s all about living life to the full.”

Local clubs for people with disabilities can help you stay active, for as long as you want to be involved. This can open up new opportunities, with a wide range of supported activities from sailing and riding, to swimming and music sessions. In most cases, support can be adjusted to meet your changing needs.

“ I’ve just finished doing an HND in fine art... I have an exhibition in May. It’s amazing and so cathartic. When I’m at the easel I’m not A. Smith with MND, I’m A. Smith the artist.”

You may also wish to seek out spiritual or religious support. Whether as part of a faith, a different type of belief or none, most people tend to ask ‘Why?’ when they are unwell and you may find it helpful to talk this through.

See later heading in this section, *Spiritual and religious support.*

There may come a time when you no longer feel that you want to travel far from home and activity becomes more limited. This can also have an emotional impact, as it may feel isolating. At this stage your immediate environment, communication ability, equipment, assistive devices and in-house entertainment become important to maintaining social links and the best possible quality of life.

This may need planning too. For example, assistive equipment can take time to arrange, deliver and install, so try to think ahead about your future needs. Always get an independent assessment of your needs first, before purchasing any equipment or assistive devices. This should be done through a relevant and qualified professional, such as an occupational therapist (OT). This can help you avoid costly mistakes. Some items may be available free through statutory services (through government or NHS funding).

How do I access professional help?

“ During this difficult and stressful time, it would have been helpful to have had a family counsellor... the challenge is to find support from someone who understands the issues being faced.”

If you are feeling particularly overwhelmed, ask your GP for guidance. You may be referred to a counsellor or psychologist, although there is often a waiting list. Your GP may be able to offer an alternative, such as referral to a support worker and many health and social care professionals can advise. Be aware that some counselling services may be free through the NHS or social services, but others may charge.

See also *Spiritual and religious support* later in this section.

If you have not been referred so far to a palliative care team or hospice, ask your GP if it can be considered. If you are planning ahead, this referral may provide access to wider services to guide you through end of life decisions and help you and those close to you manage the emotional impact.

Depending on your needs, this could include:

- counselling or psychological support
- spiritual or religious guidance
- access to complementary therapies
- family discussion of sensitive subjects, with professional support.

These services may not be offered automatically, so do ask your GP or palliative care team what is available and how to make the necessary appointments. If there is a waiting list for a service, don't let this deter you – should you reach crisis point at any stage, it is better to be progressing on a list than try to arrange support at short notice.

Who else can I talk to?

At times, you may need a listening ear outside of your immediate circle.

“ Sometimes I need to scream and there's no-one to scream to.”

Although health and social care professionals can help, they may only be available through appointment. So who can you contact if you need someone to talk to immediately?

The MND Association is here to help you in any way we can, through:

MND Connect: our helpline team can direct you to our services, external support or just provide a listening ear.

Association visitors: our voluntary visitors (where available), can provide support, guidance and information by telephone, email or through face to face visits.

Regional care development advisers (RCDAs): our regional professionals can support and guide when your needs are complex, and help to coordinate services on your behalf.

MND Association branches or groups: where informal support meetings are often arranged for people living with MND, or their carers. This enables you to share ideas and experiences with other people affected by the disease. If you decide this is not for you, it may be something to consider at another time.

Our online forum: which provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can view the forum conversations without joining if you prefer. Although your experience of MND is unique to you, there will be many examples of shared issues and practical tips.

See [Section 15: Help from the MND Association for information about our care related services and contact details.](#)

Spiritual and religious support

When approaching end of life, you may think about spirituality more, whether or not this is linked to faith. In short, you may be trying to make sense of life and death. This may include trying to resolve any conflict in your life or asking questions such as, 'Why me?', 'Who am I?' or 'What will happen after I die?'

Religious belief and spirituality can be expressed in a variety of ways and for many people this will include ceremony, rites and worship, particularly as part of a practising faith or religion. Others may explore spirituality outside of religion, through:

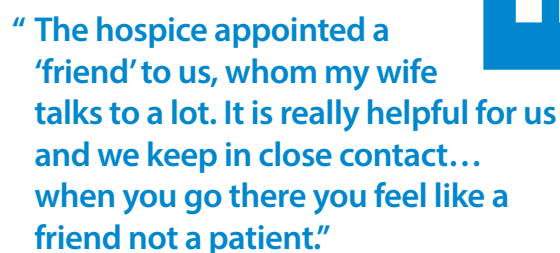
- cultural influences
- meditation and ritual
- deepening relationships and trying to understand how you relate with others
- interests of more than a functional nature, eg music, art, sport or a sense of the environment
- humanist or other beliefs
- therapies that aim towards general wellbeing.

If your identity has relied, at least in part, on what you have been able to do in life, you may find yourself seeking alternative meaning as your roles and purpose change with the progression of your illness.

You, and those close to you, may find it useful to:

- identify sources of strength you can draw on
- decide whether those sources will be helpful during this period in your life.

You may like to have support or guidance beyond your immediate family and friends. There is no guarantee that this will bring resolution, or heal psychological, emotional or spiritual pain, but it may give an opportunity to talk about your concerns at a detailed level and invite a wider view. For example, if you are linked to a hospice they can often provide counselling or more informal opportunities to talk.



“ The hospice appointed a ‘friend’ to us, whom my wife talks to a lot. It is really helpful for us and we keep in close contact... when you go there you feel like a friend not a patient.”

There are multiple avenues where you can find this type of guidance:

Specialist palliative care professionals: are skilled in communication and assessment of your needs relating to end of life support. All palliative care professionals are usually trained to be aware of the religious or spiritual needs of the individuals they support and should be able to direct you to appropriate guidance, but specialists may have a wider knowledge of external sources of help.

Hospice services: can offer listening, counselling and redirection to appropriate spiritual or religious guidance. If required, this is provided in conjunction with practical palliative and end of life care. Hospice services involve specialist palliative care professionals and volunteers.

Community faith leaders: can offer guidance and will be able to discuss questions about belief. Do not feel embarrassed if you no longer follow a faith, but would like to ask for their support. However, despite their natural association with births and deaths through ceremony, they may not be trained in end of life care or understand MND, so may not be equipped to answer practical concerns about the process of dying.

Representatives of other beliefs: can help you to consider spirituality without religion or faith. This may involve exploring your beliefs within a different framework such as Humanism. Again, they may not be trained in end of life care or understand MND, so may not be equipped to answer practical concerns about the process of dying.

Hospital chaplains: offer a multi-faith service with face-to-face visits to help you explore any spiritual concerns while in hospital. This listening and support service is open to multiple faiths or spirituality according to other beliefs.

Social workers: are trained to consider cultural needs, faith and other beliefs. They can advise you about how to find specific help and guidance.

Specialist organisations: can be useful sources of information and support. Depending on their aims, they may provide a platform for debate, a helpline, directions to other services, guidance or resources. Ask your health and social care professionals for suggestions. These organisations may be linked to a religion, belief or general end of life concerns, such as The National Council for Palliative Care (NCPC) or Dying Matters.

See Section 16: Useful organisations for contact details and descriptions of these organisations.

When the time comes, you may have religious or spiritual requirements you want observed during or following your death. You may not want to leave it all to your family or those close to you to sort out. These requirements may be very important to you and you may worry about how they will be met. Talking to funeral directors will help you find out what is possible regarding any service or ceremony held after your death, and how your needs can be best met. You may need specialist services to observe particular cultural rites.

See Section 10: What happens after I die?

Spiritual or religious concerns can also impact on your decisions about medical care and future withdrawal of treatment. You can ask specialist palliative care professionals to help you think about this in connection to your beliefs. This will help you to understand what will happen and what will not happen if you make a decision. You may then wish to consult with a faith leader to determine a course that feels right for you.

See Section 9: Advance care planning and advance decisions.

If you would like further assistance on where to go for spiritual or religious support, the MND Association can help to direct you to appropriate sources through our helpline, MND Connect, and other services.

See earlier heading in this section, Who else can I talk to? for contact details.

Changes to behaviour and emotion

Some people with MND show behavioural changes, such as restlessness, lack of drive, acting impulsively, eating lots of sweet foods, fixating on one activity or routine, or lacking empathy for others. If you have noticed any changes, there can be a variety of causes:

- the emotional impact of the diagnosis
- breathing and respiratory problems, which can make it difficult to sleep well and cause fatigue
- general tiredness from the extra effort required if movement and mobility have been affected
- frustration and anger, as symptoms and disability increase
- infections, such as chest or urinary infections, which can lead to confusion
- a symptom called emotional lability, which affects some people with MND, where you tend to laugh or cry at inappropriate times
- changes to thinking and behaviour (called cognitive change), which affect some people with MND.

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

See section 9: Advance care planning and advance decisions under the heading Do I need anyone to act on my behalf?

What is emotional lability?

Emotional lability is a symptom of MND (sometimes called pseudobulbar affect), but does not affect everyone with the disease. It can set off unexpected emotional reactions, caused by the effects of MND between the outer layer of the brain and the brain stem.

If this happens to you, it can leave you feeling out of control. It can also be distressing for those close to you, who may not understand. Your responses may not match how you feel. For example, you may laugh uncontrollably when you are feeling sad, or you may cry when you are feeling happy.

If you have this symptom when trying to deal with end of life decision making, it may place additional pressure on conversations that already feel difficult.

Will this keep happening?

In many cases this is a temporary symptom that reduces over time. If the responses are persistent and cause distress, discuss this with your GP. If your GP is not familiar with emotional lability, ask for guidance from a health and social care professional with experience of neurological conditions.

You may find that understanding the symptom is enough to help you and your family to manage the impact. Others find it limits where they go and what they do, but medication or other assistance can help.

It is more common to experience emotional lability if your ability to think and reason have been affected. However, emotional lability does not necessarily mean that changes to thinking and reasoning will happen.

Sexual expression and intimacy

For many of us, physical intimacy is very important. Touch and being close to your partner can be an essential part of showing affection and sharing emotional support. Intimacy does not necessarily always include

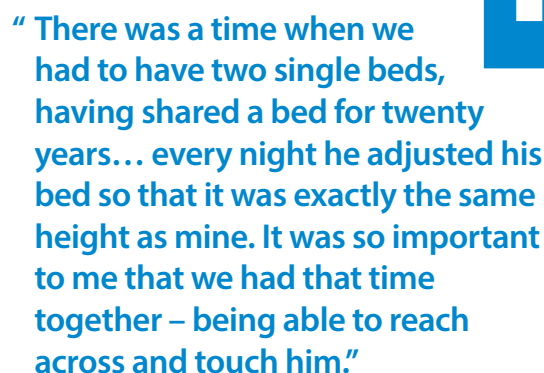
sex, but sex may be a significant part of your emotional life.

Many people affected by MND worry about the impact of the disease on sexual expression. MND does not affect sexual function, but impaired movement can make sexual expression more difficult.

If your partner is also your main carer, and they provide your personal care, this can also impact on the intimacy of your relationship.

Where end of life decisions are concerned, this can become a greater issue. For example, treatments may involve clinical equipment, such as breathing machines, feeding tubes or profiling beds (beds that can be adapted for positioning). This can impact on confidence, body image and self esteem, and create worry about the equipment itself.

However, open discussion with your partner can be very helpful and your health and social care team can provide guidance.



“ There was a time when we had to have two single beds, having shared a bed for twenty years... every night he adjusted his bed so that it was exactly the same height as mine. It was so important to me that we had that time together – being able to reach across and touch him.”

You and your partner may have questions about how MND will affect intimacy and how you can solve these issues. We provide helpful and candid information if you have concerns.

See [Further information at the end of Part 1: What do I need to think about?](#) for a list of additional publications.

Key points

- Even if it feels hard to talk about end of life, do try to have these conversations early. If MND affects your speech and communication, discussion may become more difficult.
- You cannot change the diagnosis or prevent what will happen, but you can help to ensure your wishes are respected. Confronting end of life is the most positive action you can take, so that when the time comes, you can die with dignity and with as little fear as possible.
- If you do feel overwhelmed, find someone to discuss this with. It can be a family member, a friend, a health or social care professional, someone at the MND Association, or members at a branch or group meeting. You can also join our online forum to share experiences with a wider community affected by the disease.

See Section 15: *Help from the MND Association* for information about our care related services and contact details.

3: Difficult conversations with professionals



This section explores how to manage difficult conversations about end of life with your health and social care team.

Should professionals start these conversations?

The NICE guideline on MND, from the National Institute of Health Care Excellence, recommends that professionals discuss end of life care when you or your family ask them to do so. Also, when decisions on relevant treatments are going to happen.

See [Further information](#) at the end of this section, for more about the NICE guideline on MND.

However, most of us find end of life a difficult subject to bring up in conversation and this is no different for health and social care professionals. This is why palliative care services are important, as they involve professionals who are trained to help you manage a life shortening illness. They are more likely to open conversations with you about planning ahead, and death and dying.

Other members of your health and social care team may not broach end of life, unless they feel you are happy to do so.

are giving them ‘permission’ to explore this subject with you. This can be of great benefit as it means you can gather more information about the options available to you, both now and in the future.

“ Two interesting things that I think professionals should bear in mind are: 1) the MND is not their fault, and 2) It’s not the professional’s diagnosis, it belongs to the patient.”

Who am I likely to meet?

Most health services are initially accessed through your general practitioner (GP).

Please note: as MND is a rare disease, many health and social care professionals will never come into contact with MND, or will see very few cases. An MND Care Centre, Network or local neurological service can provide support from a coordinated team of professionals with experience in the disease, usually referred to as a multidisciplinary team (MDT).

See [Section 6: What care is available?](#) for more detail about MND Care Centres and Networks, MDTs and the types of care available.

Throughout the course of the disease you are likely to meet some or all of the following:

- consultant
- specialist palliative care team members
- neurology or MND specialist nurse
- MND coordinator

“ In our case the subject was never raised and we wish it had been. It would have been helpful if someone had sat down with both of us and said, ‘these are the things you need to be thinking about’. It’s not pleasant having to think about and face these things, but it’s necessary.”

You can help by asking them direct questions. By opening the conversation, you

- community nurse
- speech and language therapist (SLT)
- dietitian
- physiotherapist
- occupational therapist (OT)
- counsellor
- psychologist or neuro-psychologist
- pharmacist
- complementary therapist
- wheelchair service representative
- social worker
- benefits adviser

See Section 6: *What care is available?* for a breakdown of these roles.

What could I include?

You should feel confident to ask any question you need to ask and to steer conversations to the subjects you feel ready to consider.

“ I believe the earlier you start to consider the reality the better...I think an informed position of the potential pathways that stretch ahead is beneficial to all, including close family and friends.”

It is your right to have your preferences, wishes and needs considered and respected, and it is only through discussion that you will be able to determine what you really want to happen.

“ Message to professionals: You can't make it better, but you can make it easier.”

One thing you need to seek is honesty. If a professional is overly concerned about causing distress, there can be a temptation to soften an explanation to the extent that it might be misleading. This could alter your

decision making. Ask them to be plain and truthful in their responses.

If you feel the conversation is going too fast, or the professional becomes too abrupt, always say so. Both you and the professional are trying to navigate through very sensitive issues. This can be tricky for you both.

“ I believe that people have defences for a reason, and what is important is to make it safe enough for them to let those defences down, even if only for a brief conversation.”

It may take a little time to work out how best to manage the questions and answers. Everyone is different and will need an individual approach. You should not be frightened to help shape the way this happens – this is your discussion.

“ One thing to note is that we're all individual. No two people will handle these conversations in the same way.”

Should I write things down?

Taking a prepared list of questions to an appointment can be very helpful. It ensures you won't forget to ask something that is important to you.

If you have difficulties with speech and communication, or worry about becoming emotional, you can hand the list of questions to the health and social care professional to read and answer.

It is also useful to write down their answers or ask the professional to make notes for you. If your main family carer is with you, they can also help if needed. You may wish to refer back to these notes at a later date.

Another option is to ask the professional if they are happy for you to record the discussion, so that you can listen to it later. You can use most mobile phones, smartphones and computer tablets to do this. It may enable the conversation to flow more easily than stopping to make notes and you won't miss anything.

What questions should I ask?

If unsure how to begin, ask a general question such as:

'I'm thinking about my future care, can you help me plan ahead?'

Or

'I'm frightened about something, can you help?'

If discussing interventions, ask questions about the impact:

'Can this intervention be withdrawn at a later stage if I don't want it anymore? How would that be managed?'

'Can I ensure I'm not given treatments if I don't wish to receive them or resuscitated if I don't want that to happen?'

See Section 4: What to expect as the disease progresses and Section 9: Advance care planning and advance decisions.

You can ask questions to help discussion with others, such as:

'Is there anything my family and friends need to know about this treatment?'

" When professionals use clinical terms or avoid discussions about death, it makes it even more difficult for families and friends. It helps when professionals have good communication skills in this area and use language we can relate to."



If you do not understand something, ask the professional to reword in plain English. It is important to know what may or may not happen before making decisions.

If a response doesn't answer your question, such as, 'Don't worry, we'll look after you,' ask more questions to get the detail you need.

Are there publications that might help?

Selected publications can help at appointments. For example, this End of Life Guide can help raise relevant questions. Our information sheets can open discussions about symptoms and care.

See Further information at the end of each main part of this guide for recommended information sheets.

The NICE guideline on MND, from the National Institute for Health and Care Excellence, sets out recommendations to professionals about treatment and care with MND. We provide information and resources to help you use these guidelines to get appropriate care. See www.mndassociation.org/mycare

The National Council for Palliative Care (NCPC) provides a booklet in their *Difficult Conversations* range, called *Making it easier to talk about the end of life with people affected by Motor Neurone Disease*. This includes quotes from people affected by MND, so professionals know what to expect when discussing end of life decisions about MND. Your needs may be different to someone else, but these shared themes can be helpful. Refer your GP, consultant, specialist nurse or other contact to the NCPC website:

www.ncpc.org.uk/difficult_conversations

If you are disabled and need health or social care service information in a particular format, ask for this help at or before appointments. This provision is now mandatory in England - for more details, search for *accessible information standard* at www.england.nhs.uk

Key points

- If a professional asks you a question such as, 'Is there anything you're worried about?' it may be a gentle prompt to see if you are willing to talk about end of life concerns. If you feel ready, this could be a good opportunity to begin discussions.
- If you are not given an opportunity to talk about end of life decisions, you may need to ask for this help, either by referral through your GP to a relevant palliative care specialist or during an appointment with a professional who can support you.
- Health and social care professionals can also contact our helpline, MND Connect, for guidance and information.

See [Section 15: Help from the MND Association](#) for contact details.

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 1: *What do I need to think about?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 6A: Physiotherapy
- 6B: Complementary therapies
- 9A to 9C: our range of sheets on thinking and emotions in MND
- 10A to 10G: our range of sheets on financial and social care support
- 11D: Equipment and wheelchairs
- 12D: Planning a holiday
- 13A: Sex and relationships for people living with MND

13B: Sex and relationships for partners of people living with MND

14A: Advance Decision to Refuse Treatment (ADRT)

From our other publications:

What I should expect from my care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Eating and drinking with motor neurone disease a guide including easy-swallow recipes and information about nutrition with MND.

Caring and MND support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

Caring and MND quick guide a small A5 booklet to help someone new to the caring role become aware of available support.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

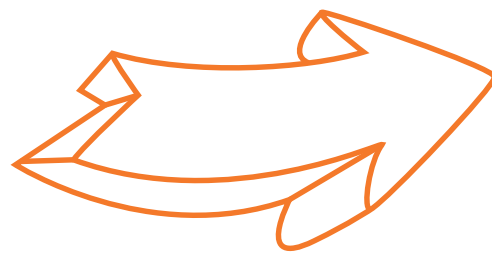
MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See [Section 15: Help from the MND Association](#), for details about our services.

Online forum:

Hosted by the MND Association at: <http://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

4: What to expect as the disease progresses



This section explores the progression of MND, end of life symptoms, and the options available for the introduction and withdrawal of treatment.

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.

“ I think it’s important for me to understand, broadly speaking, what will happen and what the main decisions, options and changes will be.”

MND affects your motor neurones, which carry messages from your brain to your muscles to tell them what to do. Muscles that no longer receive these messages stop working. How you walk, talk, grip, eat, drink, swallow, breathe and think can all be affected.

Any disability that you experience is likely to get worse over time.

Although MND is incurable and cannot be reversed, there is much that can be done to manage symptoms and make your life as comfortable as possible.

See Further information at the end of Part 2: What is likely to happen? for other publications on general symptoms and facts about the disease.

How will the disease progress?

Everyone experiences MND in a different way. The range of symptoms and speed at which they progress varies from person to person, but can be rapid. You may have

serious problems at the start of your illness or these could take time to develop.

The way symptoms start with MND is unpredictable and it is unlikely that you will have the same symptoms in the same order as someone else with the disease.

Early management of symptoms (as soon as you notice any changes), will help you to cope with the impact and maintain the best possible quality of life.

“ I would like information on how the disease progresses... and what the future loss of bodily use is likely to be. Or shall I say, ‘what the future may hold for me!’”

The symptoms described in this section can happen throughout the course of the disease, not just at end of life. However, we have focused on the main concerns expected in the later stages of MND:

- mobility and movement
- speech and communication
- breathing
- swallowing
- changes to thinking and reasoning (known as cognitive change)

We also look at some of the other concerns you may have.

This information will help you understand what may happen and what can be done to reduce discomfort as the disease progresses. However, we recommend discussing your individual circumstances with specialist palliative care professionals for guidance.

“ I was told in full what to expect from life with MND. This has helped me to decide how my life is lived and has included end of life decisions.”

Mobility and movement

How will this affect me at end of life?

Some people remain mobile during the course of the disease (particularly if the disease starts in the face, throat or tongue). However, you may find your movement is severely affected in the later stages.

If you have increasing muscle weakness, it is likely to affect the use of your arms, hands and your ability to grip, as well as your mobility. For example, you may find it increasingly difficult to feed yourself, perform daily routines or transfer your body weight, eg from bed to chair.

“ I can see that I’m changing. I can’t hold things with my right hand... I can’t do all the things I want to do.”

What can be done to help?

If your mobility and movement are affected, you will need help with your care. As your needs increase, it may not be possible for your main carer to manage this alone. In

the later stages, you are likely to need someone with you at all times. Your care may be complex depending on the medical help needed.

You may feel great frustration as your independence reduces. Some people tell us that this can feel humiliating and can impact on confidence and self-esteem. If this affects you emotionally, talk to your GP and health and social care team for advice. Again, planning ahead can help you manage some of the difficulties and feel more prepared.

“ I have found it enormously beneficial for me to consider the losses before they arrive.”

You may need to adapt your approach to daily activities. Accepting that you need equipment and assistive aids may feel difficult at first. However, this can help you maintain independence and your interests for as long as possible.

A physiotherapist or occupational therapist can assess your physical needs and advise on equipment and aids. Mobility aids such as wheelchairs, head supports, arm supports and hoists can make a big difference to your independence and what you can do. You may also wish to consider a riser/recliner chair and a powered bed for ease of positioning when sitting or sleeping.

Try to consider your future needs when looking at equipment, particularly when adapting your home. For example, a stairlift may not be the best choice if you are likely to need a wheelchair, as this would require two wheelchairs, one for each floor. You will also need to transfer between the wheelchair and stairlift, which may become difficult for you and your carer in the later stages.

A through-floor lift or a downstairs conversion may give easier access and there may be local authority or charitable funding to assist. Ask your occupational therapist for advice.

See also Section 15: *Help from the MND Association* for details about how we can support you with equipment and funding.

What should I consider when planning ahead?

Talk to your health and social care team for advice about mobility and movement. This may include guidance on:

- assessment of your needs, and those of your carer, by adult social care services, to help arrange appropriate care support at home and look at your future needs (your income and savings will be assessed to see if you need to make a contribution to any services you receive)
- assessment by a physiotherapist or an occupational therapist for access to aids to help you with mobility and movement
- assessment by an occupational therapist for an appropriate wheelchair
- home adaptations, which need planning early, as these can take a long time (particularly if you seek funding through a Disabled Facilities Grant)
- respite care arrangements to give your carer rest or time away from home
- residential or nursing home care if your needs are particularly complex or your main carer is unable to provide increasing levels of support at home.

See Section 6: *What care is available? for types of care and who can support.*

Speech and communication

How will this affect me at end of life?

Where speech is affected, this is likely to get worse over time. This may be due to breathing difficulties, which can reduce the volume of your speech. Your face, throat and tongue muscles may also weaken, which can change how you speak. If you find it more difficult to gesture or use facial expression, this will also make communication more challenging.

What can be done to help?

A notepad and pen can help you to communicate at first, but writing can become difficult if your grip is affected. Speech and communication aids can assist, from simple printed word or image cards, through to computer technology (which can be adapted for use with limited movement). A speech and language therapist with knowledge of MND should assess your needs, as not all items suit everyone. Some are costly and you may find that inexpensive and simple solutions can provide effective help.

What should I consider when planning ahead?

You may already use a computer and special applications to help you communicate or use the internet. Adapted controls can help you continue using this technology as physical disability increases. However, be prepared that in the later stages:

- you may find them more difficult to use
- some equipment may not be as easy to use in different locations, such as in hospital if you need treatment
- there is a possibility that these could fail to work, leaving you without a means to communicate when your needs are more complex.

If you already use computer technology, try to practise with basic aids, such as an alphabet board, as a back-up method. This way, you have an additional, simple way to communicate wherever you may be. Ask your speech and language therapist for guidance.

We recommend discussing your wishes about end of life with your main carer, family and health and social care team if you begin to experience any problems with speech or communication. As this gets worse, conversations are likely to become more difficult, particularly if some of the health and social care professionals you meet have little or no experience of MND.

You may wish to put advance care plans and advance decisions in place before your speech and communication get worse.

See Section 9: Advance care planning and advance decisions.

If you already have severe speech and communication problems, specialist palliative care professionals or other members of your health and social care team can help you with planning. Your main carer can also help ensure your wishes are understood.

Breathing

How will this affect me at end of life?

The muscles you use to breathe tend to weaken as the disease progresses. Symptoms and signs may include:

- disturbed or non-refreshing sleep
- shallow breathing, even when at rest
- difficulty breathing when lying flat
- repeated chest infections
- a weak cough or sniff
- morning headaches
- daytime sleepiness and feeling very tired
- confusion, poor concentration and/or memory
- poor speech volume
- excessive use of muscles in the upper chest and neck.

What can be done to help?

Ask your health and social care professionals for advice, particularly if you have access to a respiratory consultant, neurologist, physiotherapist or specialist palliative care professional. They can advise on breathing therapies and techniques, ways to relax, positioning to ease breathing, how to save energy to make the most of the way you breathe and the types of mechanical breathing support available.

You may also be prescribed medication if suitable. Symptoms such as breathlessness

can feel worse if anxiety increases and medication can help ease these feelings.

Pressure on your breathing may be relieved by using a riser/recliner chair, wheelchair, powered bed or other assistive equipment. You can also try increasing the number of pillows you normally use, so that you don't lie flat at night.

If breathing problems increase, you may need to consider the following:

MND Just in Case Kit: is a box you can keep at home, to contain medication for use in emergency situations. Having a kit nearby can be reassuring should you become breathless or have bouts of coughing or choking. We supply the box free of charge to your GP, at their request. Your GP then prescribes suitable medicine for you to keep in the box. This ensures medication is on hand, for a doctor or district nurse, if they are called out of hours. It also provides guidance and (if your GP feels it is appropriate), medication for your carer to give to you while waiting for professional medical help to arrive.

See Section 15: Help from the MND Association for details of how professionals can contact our helpline MND Connect for assistance.

Mechanical breathing support: is where a machine either supports or takes over your breathing. This can be introduced using:

- non-invasive ventilation (NIV), where a portable machine supports your own breathing by providing extra air through a mask over your nose, or over your nose and mouth. This support is usually needed for short periods at first, or overnight, but as the disease progresses you may become reliant
- invasive ventilation (tracheostomy), where a machine takes over your breathing through a tube inserted into the windpipe through the neck.

Mechanical breathing support is not suitable for everyone, but if appropriate, it may help relieve respiratory distress, improve sleep and reduce fatigue.

Risk with use of oxygen: in most cases, ventilation for MND uses normal air to help you breathe. Extra oxygen is not usually recommended with MND, as it can upset the balance in your body between oxygen and carbon dioxide. However, if your oxygen levels are low, it may sometimes be used with caution. Any decisions regarding oxygen for home use should be discussed with your respiratory team, as high levels of oxygen in your blood can be harmful.

See Further information at the end of Part 2: What is likely to happen? for details about our MND alert resources and our range of information sheets 8A – 8E on breathing and ventilation with MND.

Weak cough: if your cough weakens, support can be given. This might include ways to increase the amount of air you take in, with a technique called breath stacking and the use of lung volume recruitment bags. You may also be offered a machine to assist your cough and help you clear mucus. Your health and social care team can advise.

Flu vaccination: chest infections can make breathing difficulties worse and increase mucus. Try to avoid people with colds or flu and request a flu vaccination from your GP. It can't stop colds, but does reduce the risk of flu.

The flu vaccination is usually available from October and you need it every year. You'll be checked to see if it's right for you. You may feel slightly unwell after the vaccine, but it won't give you flu. Ask your GP if your family can also have the vaccine to help protect you.

What should I consider when planning ahead?

You will be assessed to see if mechanical breathing support is suitable for you. You may or may not find the mask comfortable, but it is your choice to use this type of support.

Breathing support may reduce some of the symptoms of MND, but will not stop muscle weakness in your body from getting worse. This is likely to affect your quality of life.

There may come a time when you feel that breathing support is no longer helping or it has become a burden. You can ask for it to be withdrawn, even if this may shorten your life. If you have become reliant on ventilation and you are approaching end of life, death is likely to happen in a relatively short time following withdrawal of this support. This can vary depending on how weak your breathing has become. Your respiratory consultant or specialist palliative care professionals can advise. Medication before and during withdrawal can help you feel calm and relieve distress.

See Further information at the end of Part 2, for details about our information sheets on breathing, ventilation support and withdrawal. See also Section 5: How will I die?

You can record which treatments to withdraw, and precise circumstances in which you want withdrawal to take place, using an Advance Decision to Refuse Treatment (ADRT). A valid and applicable ADRT is legally binding, but will only be actioned if you become unable to make decisions or communicate. Tell everyone involved in your care about the ADRT. If they are unaware, they will not be able to use it.

See Section 9: Advance care planning and advance decisions for more detail on why an ADRT might be needed and how to complete the form.

It is also helpful to draw up advance care plans to tell health and social care professionals about your general needs and preferences. This is not legally binding like an ADRT. Not all professionals have experience of MND, so it can help guide how you are cared for, particularly in emergencies where you may not be able to communicate.

“ He was taken into hospital with a chest infection but they didn't really know what to do with him because the specialist nurses and the consultant were unavailable.”

For example, invasive ventilation (tracheostomy) is often used temporarily to help someone recover if resuscitated in an emergency. The emergency team may not realise how difficult it can be to stop using this type of ventilation if your breathing muscles have weakened with MND. You may then have to accept this type of ventilation as ongoing support, which can affect plans for your future care.

If invasive ventilation (tracheostomy) is something you definitely do not want in any circumstances, you need to make this clear to all those involved in your care. An ADRT may help you to do this.

Our *MND Alert Card* can also support you in emergency situations and has been included in the End of Life guide folder. It can be kept in a wallet, purse or pocket. If you are admitted to hospital for any reason during the course of the disease, it alerts staff that you have MND and directs them to key contacts for the specialist help you may need. Our MND Alert Wristband can also help flag that you have MND and that you may be at risk with use of oxygen.

“ Another thing that is really comforting is having a card with contact details...They told me that should I need to go into hospital I should show the card. The people concerned will then contact my consultant and the MND Coordinator.”

We also produce an *Understanding My Needs* leaflet which you can use to write down a summary of your needs for use in hospital or during respite care.

See Further information at the end of Part 2: What is likely to happen? for details about how to order additional publications, such as our *MND Alert Card* and the *Understanding My Needs* leaflet.

Swallowing

How will this affect me at end of life?

If you experience difficulty with swallowing, it may:

- affect how you eat and drink and you could lose weight
- make it more difficult to swallow your saliva (which can lead to drooling)
- affect how you take any medications you need (your GP can advise about different ways to receive these)
- increase the risk of food and drink entering the lungs (known as aspiration), which can lead to chest infections or aspiration pneumonia. Combined with a weakened cough, chest infections can be distressing and may happen repeatedly.

Swallowing difficulties can also lead to mild choking (where the airway is partially blocked) or, very rarely, severe choking (where the airway is fully blocked).

What can be done to help?

You may wish to consider:

- using prescribed medication or over-the-counter remedies to relieve thin saliva, thick saliva or a dry mouth (your GP can advise on other ways to manage this)
- finding out how you and your carers can manage repeated coughing or choking, should this happen
- keeping a JIC Kit at home for emergency situations

See earlier heading, *Breathing for more detail on the JIC Kit.*

- asking your health and social care team about having a feeding tube inserted through the front of your abdomen directly into the stomach, to receive liquid food, medication and fluids (known as a gastrostomy).

See Further information at the end of Part 2: What is likely to happen? for a list of relevant publications on swallowing difficulties and alternative eating methods.

Tube feeding helps you to:

- receive the level of nutrients that you need
- reduce the risk of bits of food and drink entering your lungs, as you no longer have to eat and drink through your mouth (although it cannot prevent all risk of chest infection)
- receive medication in liquid form
- reduce the time needed to eat, which can become lengthy and tiring
- reduce stress for both you and your carer at mealtimes

If you have a feeding tube, you do not have to use it immediately. You can eat and drink normally, for as long as you feel safe or comfortable. You can also taste small quantities of food and drink, while using the tube to receive the correct amounts.

At a later stage, you can use the tube for all of your food, fluids and liquid medicines.

If you live alone, it may be difficult to get the correct level of care required for a feeding tube.

What should I consider when planning ahead?

If you want to consider tube feeding, discuss the benefits and risks with your GP, dietitian and speech and language therapist in order to make the right choice for you.

See Further information at the end of Part 2 - What is likely to happen? for details about our resources on swallowing, tube feeding, and eating and drinking. Also, how to access the MyTube website for tube feeding videos.

Timing is important. Tube insertion requires a hospital procedure, which carries more risk if breathing problems get worse. There may come a point where it is no longer possible for a tube to be introduced.

If it is felt to be no longer helping or has become a burden, you can decide to stop receiving food by tube at any time, should you wish to do so. This can be combined with other decisions to refuse life-sustaining treatment.

“ I asked my consultant the timetable for dying if I could no longer eat or drink. He was very straightforward and clear in his answer.”

When nearing the end of life, the body usually requires less food, whether taken orally or through tube feeding. This means that deliberately reducing or stopping the intake of food may not feel as uncomfortable as can be feared. Your family and carers may find it upsetting if they see you losing weight, but there is no need for them to encourage you to eat in the final stages. As you get closer to dying, you will be less likely to digest food properly and you will not feel the need to eat.

You can continue to receive water by tube to prevent dehydration if you wish, which may help you remain comfortable. If you have never had a tube fitted and can no longer swallow fluids, it can be helpful to keep the mouth and lips moist with a wet cloth or tiny amounts of water. Ask the professionals supporting you for advice.

If you are worried that you may not be able to express a choice for reducing or stopping intake of food in the future, you can record your wishes by using an Advance Decision to Refuse Treatment (ADRT), specifying the precise circumstances in which you would want withdrawal to take place.

See Section 9: Advance care planning and advance decisions.

Changes to thinking and behaviour

How will this affect me at end of life?

It is now recognised that about 1 in 2 people with MND may have some changes to thinking and behaviour (known as cognitive change), as part of the disease itself. In most cases the changes are mild, but if more serious, the ability to make decisions may become more difficult.

The person affected may not be aware of changes, but family or a carer may notice different behaviour. However, changes may be due to other reasons, such as depression, poor sleep and emotional reactions to longterm illness.

Some people with MND also have unexpected emotional reactions, where they find themselves laughing or crying for no particular reason (known as emotional lability). This is more common if thinking and reasoning have been affected, but these emotional reactions can happen even when thinking processes are normal in MND.

See Section 2: Emotional and psychological support for more about emotional lability.

A small minority of people develop a type of dementia called frontotemporal dementia (FTD), which is likely to involve more severe changes to reasoning and behaviour. These changes can be very difficult for the main carer to manage. Additional care support is likely to be needed.

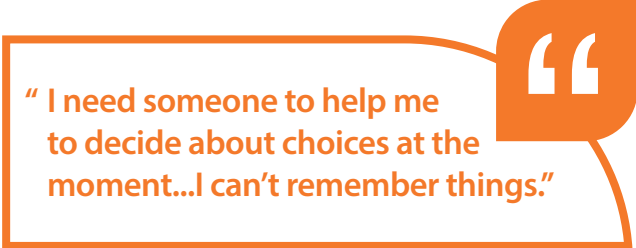
See Further information at the end of Part 2: What is likely to happen? for detailed information about changes to thinking and emotions.

What can be done to help?

Talk to your health and social care professionals, in particular your neurologist, for advice and ways to manage any symptoms relating to changes in thinking, reasoning or behaviour. Depending on the circumstances, you may be referred to other specialists, such as a clinical psychologist, usually with a specialist knowledge of neurological conditions, or a clinical neuropsychologist. They may be able to suggest ways to manage the impact for you and your family.

Make sure you are given plenty of time to understand any issues and ask for the professional to write down any important points or record the conversation (most mobile phones enable recording or you could take along another device). This will help you to remember what has been said.

Some symptoms may have other causes, for example you may feel very tired if your breathing has been affected and find it difficult to concentrate or retain information.



“ I need someone to help me to decide about choices at the moment...I can't remember things.”

If your main carer is likely to need more support, ask your local authority or adult social care services for an assessment of your needs and those of your carer. This will help determine what type of support you may need for personal care, including respite care to give your main carer time to rest. They can tell you what services are available and provide guidance. If you qualify for arranged services, these will be means tested to determine what contribution you may need to make.

Changes to thinking and reasoning may also affect the way you behave or react to others. You may wish to explore ways to feel calm and relaxed, which can alleviate some of the distress that may be felt. Medication can help or you can use other ways to relieve stress. For example, some people with MND find complementary therapies helpful, including activities such as music therapy.

What should I consider when planning ahead?

If you feel that it may become difficult to express your needs, wishes and preferences, try to have these discussions as early as possible.

Writing down how you would like to be cared for in the future will help to ensure your wishes are respected. Health and social care professionals can help with this.

See Section 9: Advance care planning and advance decisions.

You may also wish to get your personal affairs in order, such as making a will.

See Section 8: Putting affairs in order.

Other concerns

You may be worried about the following:

Pain: although MND does not directly affect the sensory nerves, immobility and weakness can lead to severe discomfort. Medication and other measures, such as physiotherapy, can help to control any resulting pain. The use of pressure relieving mattresses and cushions can also help, as can positioning. If you experience pain, ask your health and social care team or specialist palliative care professionals for assistance.

Incontinence and constipation: problems with the bladder and bowel are not usually direct symptoms of MND, but you may not be able to get to the toilet easily if your mobility is severely affected. Ask your health and social care professionals to advise about continence aids, a catheter or urinary sheath. Try not to cut down on fluids to avoid the need to go to the toilet, as this can lead to dehydration and constipation. They can also advise on bowel problems and constipation if needed.

“ How, where and when to go to the toilet has become more and more of an obsession as I go through my illness. The more immobile I have become, the more this question traps me...it is also much more difficult to open my bowels if I lack sufficient breath.”

Problems with the bowel can sometimes be managed through changes to diet and ensuring you receive enough fluids. Medication may be advised in more severe cases, or bowel irrigation under medical supervision, where fluids are flushed through the bowel to help it clear.

Key points

- One of the ways you can maintain control over your care is to ensure your wishes and preferences are written down. Ask your health and social care team about advance planning and advance decisions.

See Section 9: Advance care planning and advance decisions.

- Keep a log of any questions to ask health and social care professionals. This may help if you feel tired or overwhelmed at appointments. Note down answers or record the conversation to refer back to later. Ask for help to do this if needed.
- Think about how you would like your symptoms to be managed before they progress, particularly if your breathing or swallowing are affected. Talk about this with family and friends, as well as the professionals involved in your care.
- Before making decisions about equipment or aids, have your needs assessed by the relevant professional, eg an occupational therapist or speech and language therapist. Equipment may not always be suitable for everyone and mistakes can be costly. You may also be able to obtain certain items free from the NHS or adult social care services.
- You can be referred to specialists by your GP or other members of your health and social care team.
- Accepting appropriate care, equipment and adaptations can help you remain as independent as possible, for as long as possible. This can help you to save energy for the activities that are most important to you and take away some of the pressure from your main carers.
- If you feel home adaptations may be needed, think about this as early as possible, as both funding and practical arrangements can take time.

5: How will I die?

This section provides information about dying and how this might be managed with MND.



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.

“ I know I’m going to die with this...I’m not afraid of dying, but I am afraid of how I’m going to die. Whenever I’ve broached the subject I’ve been told, ‘Don’t you worry about that. We’ll make sure you’re comfortable.’ But that doesn’t deal with the fears.”

You may worry about distressing symptoms towards the end of life, such as choking. Mild or severe choking can be stressful for you and your carer at the time, but it is extremely rare for this to be a direct cause of death. In reality, most people with MND do not die from a frightening event, but have a peaceful death.

See Further information at the end of Part 2: What is likely to happen? for a list of publications to help with symptom control, including Information sheet 7A - Swallowing difficulties, which contains detailed advice on how to manage choking.

The final stages of MND will usually involve gradual weakening of the breathing muscles and increasing sleepiness. This is usually the cause of death, either because of an infection or because the muscles stop working.

Specialist palliative care services focus on quality of life and symptom control. This includes practical help, medication to ease your symptoms and support for you and your family.

“ I asked ‘How is he going to die?’ and the palliative care consultant said, ‘I think he’s going to have a respiratory arrest.’ Afterwards I said, ‘I’m not sure I wanted to know the answer to that question, but thank you for answering it.’ The consultant said that he had found that conversation difficult too. It was nice that he acknowledged this. It was just two human beings struggling with the same thing.”

When breathing becomes weaker, you may feel breathless and this can be distressing. However, your health and social care professionals, such as your GP, community nurse or members of the specialist palliative care team can support you to reduce anxiety.

You can also receive medication to help reduce symptoms as they become more severe, not just in the last stages of life. If you have any concerns about the way medication will affect you, ask the professionals who are supporting you for guidance.

Try to keep discussion open with your health professionals. If this becomes difficult, your carer or family can ask what is happening, so they know what to expect. Medication to manage symptoms in later stages may make you feel sleepy and not fully aware of people and events. It helps if your family are prepared for this. In many cases, medication can be adjusted to find a level that works best for you.

Further weakening of the muscles involved in breathing will cause tiredness and increasing sleepiness. Over a period of time, which can be hours, days or weeks, your breathing is likely to become shallower. This usually leads to reduced consciousness, so that death comes peacefully as breathing slowly reduces and eventually stops.

Sometimes the breathing pattern can change just before death, with previously deeper breaths becoming much shallower.

For people using ventilation, the palliative care team will be able to offer advice about when it might be best to discontinue its use.

Talk it through

“ I know what the end is likely to be and I’ve put that away in a mental box and locked it away. Otherwise I wouldn’t be able to enjoy the rest of my life.”

For many people, death is a difficult subject to discuss or think about. We hope this has helped you to understand what might happen in the final stages, but we also know that some people may feel overwhelmed by grief and sadness as they think about the end of their life.

You and your carer and family may find it very helpful to talk through any concerns. You may also wish to discuss your worries and fears with your GP, your specialist palliative care professionals or another health and social care professional who can continue to offer support and advice throughout end of life.

If you have an MND Association visitor, they will be able to listen and offer you reassurance. You can also contact our helpline, MND Connect, if you have any questions or need emotional support.

See Further information at the end of Part 2: What is likely to happen? for our helpline contact details.

Key points

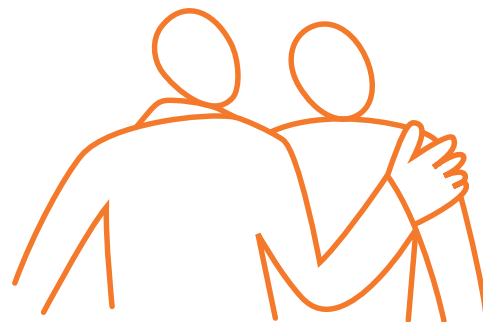
- While the thought of discussing the process of dying may seem frightening, not knowing what may be ahead may create more fear. If you are still concerned and would like more detail, ask your specialist palliative care professionals or neurological consultant for additional guidance about the final stages.
- It can be reassuring to know what type of support is available at the end of life. Symptoms can be well managed and, in the majority of cases, death is peaceful and dignified.
- Any statement you write down about your end of life care, whether by Advance Care Plan or Advance Decision to Refuse Treatment, will help those around you to understand your wishes should you become unable to communicate.
- If you have a preference about where you want to die, ensure you discuss this with your family and specialist palliative care professionals. It may not always be possible to meet your choice, but try to ensure this has been recorded in an Advance Care Plan or an End of Life Plan. There may be certain arrangements that need to be made to enable your preference. Having this written down will be helpful.

See Section 9: Advance care planning and advance decisions.

See the heading *Breathing* in Section 4: What to expect as the disease progresses for details about our MND Just in Case Kit. This box can be ordered by your GP so that you can keep medications at home to ease breathlessness, anxiety and choking.

6: What care is available?

This section identifies and explains the types of care on offer at end of life and who is involved.



“ The difficulty for the family can sometimes be to know who to go to for what symptoms or difficulties. This may seem obvious to the health professionals involved... but often it is the first time the family has to cope with a serious illness and look after someone in the home.”

Your GP and community healthcare team

Based either within a GP surgery or local clinic, this community team includes GPs and district/community nurses, but may also include professionals such as speech and language therapists, dietitians, occupational therapists and physiotherapists.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

Types of care

There are five main types of care that you are likely to use when approaching end of life:

- your GP and community healthcare team
- Specialist and multidisciplinary healthcare for MND
- adult social care services
- specialist palliative care services
- support from other organisations.

These are described below.

See also the heading *What is NHS Continuing Healthcare?* later in this section.

Please note that end of life and specialist palliative care can vary across regions and, at times, these services can be stretched.

Wherever possible, early referrals to these services can help build a relationship, so that your needs and wishes are already known if you need emergency support.

Do ask for referral to your palliative care team, as this may not be offered automatically.

How can they help with end of life care?

Depending on their expertise, they can offer assistance through:

- referrals to specialists or services
- managing and monitoring symptoms
- advising on the management and prevention of health problems
- prescribing medicines (those who are authorised to prescribe)
- accessing specialist equipment
- support for you, your carer and your family.

How do I access this help?

These services are usually provided at a surgery or clinic. Towards the end of life, you are more likely to receive these services in your own home.

“ If I need any help I can call on the local community physiotherapist, occupational therapist, GP or MND volunteer...”

Help from a GP and community nursing team is also available on evenings and weekends, through your local out-of-hours service.

Do I have to pay for this?

The majority of NHS services are free at point of delivery, but exceptions include:

- some dental and optical services
- larger items of equipment and assistive aids provided by local authorities, for which you may be financially assessed to see if you are required to make a contribution
- some prescription fees, although you would usually qualify for exemption from payment (if you live in Northern Ireland or Wales, all prescriptions are free).

See Further information at the end of Part 2: *What is likely to happen?* for details about our information sheets. Prescription exemptions and help towards the cost of sight tests and dental charges are covered in Information sheet 10A *Benefits and entitlements*.

Specialist and multidisciplinary healthcare for MND

Specialist health care professionals cover a particular area of treatment. They often work in a team based at the same location, but can work as a virtual team in different settings. Where specialists from different areas of care work in a co-ordinated way, they are known as a multidisciplinary team.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do within a multidisciplinary team.

How can they help with end of life care?

Specialists offer similar services to the community team, eg managing and monitoring of symptoms, but focused on a particular area, such as breathing support. This is likely to include help on planning ahead with regard to treatments, ways to cope, clinical equipment and your choices.

See Section 4: *What to expect as the disease progresses* and Section 9: *Advance care planning and advance decisions*.

In many areas, you may be able to get help and guidance from a coordinator who specialises in MND.

“ My MND coordinator is very thorough in keeping myself and other medical practitioners involved in my care, informing me of any new developments or findings, and answering any questions I may have.”

MND coordinators tend to be located at MND care centres and networks, as care centre coordinators, but this role sometimes exists through other neurological services, palliative care and hospices. Ask your GP or neurologist for guidance in your region.

How do I access this help?

You can be referred by your GP, or by another health and social care professional, according to your needs. Specialist services are provided in hospitals or clinics, and sometimes in your home.

Do I have to pay for this?

This type of NHS care is free.

Adult social care services

Normally based in local authority offices, adult social care services sometimes work within a surgery or clinic, alongside the local community health care team. In Northern Ireland, these services would be provided through the local health and social care trust. These services usually include social workers, care managers, care coordinators and occupational therapists (OTs).

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

How can they help with end of life care?

They can offer assistance through:

- assessing your existing and potential needs, through a needs assessment, to see what services and support you may require for everyday living
- assessing the needs of your carer, through a carer's assessment, to determine if they need support
- assessing the needs of children and young people, especially if they are involved as young carers
- arrangement of services to meet your needs, eg personal care to help with laundry, washing, dressing, food preparation and other daily tasks
- provision of small items of equipment
- advice on larger equipment, home adaptations and potential funding sources
- guidance on other services, benefits and emergency support
- psychological and family support
- guidance on selection and arrangements for residential and nursing care homes, should this be required.

How do I access this help?

Assessment for you, your carers or any young carers involved, may not happen automatically, but you can request this by contacting the adult social care team through your local authority or social services (or in Northern Ireland your health and social care trust). You can find local contact details online or in a telephone directory.

Assessment is usually done at your home. As the disease progresses, you can ask for a review should your needs change.

Do I have to pay for this?

Some equipment may be free, but you may have to pay towards care services. Your income and savings will be considered to see how much you will be expected to contribute or if you will be funded. If you live in Northern

Ireland home care services are free, but there may be a charge for other services.

Care services can either be arranged for you or you can receive direct payments to make your own arrangements, if you are being funded. We provide Information sheet 10B - *Direct payments and personalisation* to help you understand these options.

See Further information at the end of Part 2: What is likely to happen? for details on how to access other publications.

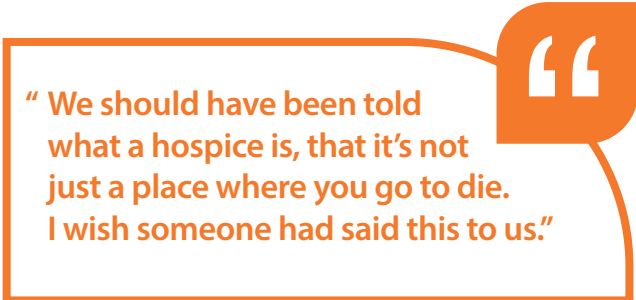
Specialist palliative care services

Based in a hospital, hospice, day hospice or local clinic, specialist palliative care is provided by a wide range of health and social care professionals. These professionals have additional training and expertise in the management of care for people with life-shortening illnesses.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

How can they help with end of life care?

Whether in a hospice or other setting, specialist palliative care services provide a more focused approach to end of life care, which considers the person's needs as a whole.



“ We should have been told what a hospice is, that it's not just a place where you go to die. I wish someone had said this to us.”

This includes symptom management, but also psychological, social, spiritual and practical support. This may range from clinical care and counselling, to the use of complementary therapies and guidance on financial support. They will also provide support for those close to you.

“ Death, especially your own death, can be a difficult subject to raise. But I found staff at the hospice were as willing to discuss death as they were willing to discuss the weather.”

How do I access this help?

Referral to these services is usually from your GP, but other health and social care professionals can also refer. Palliative care services can be provided where needed, whether in hospital, a hospice, your home or a residential or nursing care home.

Ask about early referral if possible. Depending on your progression, you may have to wait if services in your area are busy. However, the earlier you can build a relationship with a hospice or specialist palliative care services, the more benefit you are likely to receive. This also enables the professionals involved to get to know your needs, wishes and preferences. If you do have to be admitted to hospital for any reason, their knowledge of your case may help ensure you get the specialist help you need. This could mean a shorter stay.

Do I have to pay for this?

Palliative care services are usually free. These may be NHS funded or through charity funding (eg through independent hospice funding or charities involved with end of life care).

There may be some services you need to pay for. For example, you may be offered some complementary therapies free of charge, but if you wish to explore a wider selection, you may have to pay for these.

Support from other organisations

A variety of voluntary organisations can help support you and your family with end of life care. These may be local, regional or national organisations.

See Section 16: Useful organisations for some suggestions.

How can they help with end of life care?

Depending on the aim of the organisation, they can assist by:

- providing advice, guidance, information and resources
- directing you to other support to meet specific needs, such as respite care to give your carer time to rest
- offering direct help, such as equipment loan or financial support.

How do I access this help?

Contact the organisation direct. You can find contact details online, through telephone directories or ask your local authority, as they may have their own directory of services. We can also help direct you to services and organisations, through our helpline MND Connect, our Association visitors, our regional care development advisers and our branches and groups.

See Further information at the end of Part 2: What is likely to happen? for contact details for our helpline MND Connect.

See also Section 16: Useful organisations for a selection of organisations you may wish to contact.

Do I have to pay for this?

Much of the help on offer will be free of charge, but this will depend on the organisation and the type of services they provide.

Who is involved?

“ We deal with so many people. We have a list on our fridge - there are around twenty of them: consultant, palliative care, occupational therapist...I see the consultant at the national neurological centre every four to six months. We are in very close contact with the MND specialist nurse and she's excellent. We're also in contact with our GP...I was quickly transferred to the hospice. They said it was early days, but that they would be around when we need them.”

Most health services are accessed through your GP, who can help with symptom management and medication, or refer you to other support, such as:

- a symptom specialist, such as a respiratory consultant or speech and language therapist
- an MND care centre or network

See Section 15: Help from the MND Association for information about our part-funded MND care centres and networks.

- a local neurological clinic or MND service, normally within neurology, rehabilitation services or specialist palliative care. This is usually based in a local or regional hospital.

As MND is a rare disease, many health and social care professionals never come into contact with MND or see few cases. Specialist, coordinated care (from professionals familiar with the condition) is particularly helpful during the later stages, when care can be complex.

However, services can vary across regions. This is where referral to an MND care centre or network (part-funded by the MND Association), or to a local neurological service, is valuable.

The multidisciplinary team

“ I find it confusing that so many people are involved from specialisms which I don't really understand.”

Support by multiple specialists is required for MND. This is usually managed through a multidisciplinary team (MDT). All health and social care professionals involved in your care work in a coordinated way, but a multidisciplinary team is specifically set up to provide a coordinated approach. Where available, it is helpful if you have a particular professional who can act as a coordinator for your care – see MND coordinator in the following list.

The team will probably include some or all of:

Consultant: for assessment, diagnosis, symptom management Information and advice. This is usually a neurologist, but you may also meet symptom specialists, such as a respiratory consultant for breathing problems. With end of life care, you are likely to meet a palliative medicine consultant as part of a specialist palliative care team.

Specialist palliative care services: for symptom management, advice and support, counselling, emotional and spiritual support, complementary therapies and information. Specialist palliative care is designed to support the best possible quality of life during a progressive, life-shortening illness. In many cases, these services can be received at home, but are often provided through a hospice, hospital or day centre as an outpatient. Short stay admissions may be needed for assessment or palliative care support. Most services are also available for your family and your carer too.

Neurology or MND specialist nurse: for specialist advice and information about neurological conditions, such as MND. Nurses may offer home visits, clinic appointments or a combination of both and will make referrals on your behalf as and when the need arises. Please be aware that there may not be neurology or MND specialist nursing staff in all areas.

MND coordinator: for coordination with other health and social care professionals involved in your care. They answer questions and keep you informed of any developments about the disease. MND coordinators tend to be located at MND care centres and networks, as care centre coordinators, but this role also exists through other neurological and palliative care services and some hospices. Ask your GP or neurologist for advice about MND coordinators in your region.

Community nurse: for nursing services, such as assistance with medication, monitoring and treatment of symptoms, prevention of pressure sores, continence advice and provision of home nursing equipment. Working closely with your GP, they are likely to have regular contact with you towards end of life.

Speech and language therapist (SLT): for advice and assessment on speech and communication, but also swallowing difficulties. SLTs with experience of MND can advise on a range of suitable aids if your speech is affected and inform you which of these may be funded by the NHS. An independent assessment with a SLT is recommended if you consider purchasing any communication aids, as these can be expensive and not all solutions suit all people. Not all SLTs have experience with MND, but they can contact us for guidance. We provide a document called the AAC Pathway to help them assess people for alternative communication aids.

Dietitian: for advice on the most appropriate diet to help you maintain a healthy weight and for guidance where swallowing may be difficult. A dietitian will often work closely with your speech and language therapist.

Physiotherapist: for guidance on managing symptoms, such as fatigue, cramps and tightness in muscles. They can advise on appropriate exercise, passive or assisted, and positioning to maximise comfort. Physiotherapy and exercise cannot delay the progression of the disease, but they may help to maximise the use of muscles that are not yet affected and increase flexibility by maintaining movement of your joints. You may also be referred to a respiratory physiotherapist for help with any breathing problems.

Occupational therapist (OT): for advice on posture, equipment and access in your home, to help you continue daily routines with as much independence as possible.

Counselling and psychology services: for emotional and psychological support. Your GP can usually refer you to an appropriate service, counsellor or psychologist, but there may be a waiting list. Your local hospice, palliative care team or palliative care social worker may offer counselling as part of their palliative care support.

Pharmacist: for advice on the best types of medication in particular circumstances, eg many medicines can be dispensed in liquid form for ease of swallowing.

Complementary therapists: for a variety of complementary therapies, in conjunction with conventional medicine, eg massage, acupuncture, reflexology and others. For some people, the use of complementary therapies can help to alleviate symptoms and reduce feelings of stress.

Wheelchair services: for assessment of seating needs and coordination of provision for a wheelchair, as appropriate. Please be aware that there are often waiting lists for this provision. If you find this is the case in your area, our Support Services team at the MND Association can advise.

See Section 15: Help from the MND Association.

Social worker or care manager: for help with care assessments, advice, information and social care arrangements, including arranging care at home or advice regarding care homes.

Benefits adviser: for help on decisions and claims regarding benefits. The adviser may not be directly linked to a healthcare MDT, but there may need to be communication between members of the MDT and the benefits adviser, if medical evidence is needed to support a particular claim. Benefits advisers are usually contacted through your local Jobcentre Plus office or you may wish to search for government online information at www.gov.uk or in Northern Ireland at www.nidirect.gov.uk

What is NHS Continuing Healthcare?

This is often referred to as continuing care and is a package of funding and care for complex medical needs, provided by the NHS.

If you qualify, the full cost of all the care you need (whether for health or social care) will be funded by the NHS. However, in some cases, this will be provided as a 'shared care package' between the NHS and adult social care services.

In Northern Ireland there is no guidance on NHS continuing healthcare, but the health and social care trusts are encouraged to refer to the criteria used in the rest of the UK.

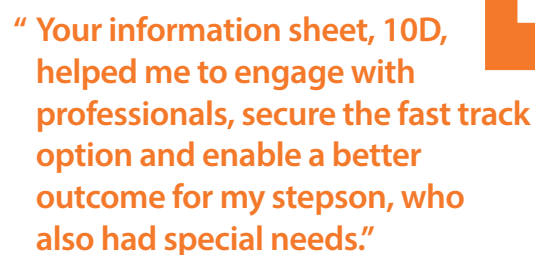
To be eligible for NHS Continuing Healthcare, your main or primary need must relate to your health. Your needs will be assessed against specific criteria to determine if you require a high level of healthcare and support for any of the following:

- complex medical conditions
- rapidly deteriorating conditions
- end of life care.

Initially, your healthcare needs will be identified by a qualified healthcare professional to determine if you should be

referred for a full assessment. The full assessment will be carried out by a team of health and social care professionals. You and your main carer should be consulted as part of the assessment process.

See Further information at the end of Part 2: What is likely to happen? for details about Information sheet 10D - NHS Continuing Healthcare.



“ Your information sheet, 10D, helped me to engage with professionals, secure the fast track option and enable a better outcome for my stepson, who also had special needs.”

Key points

- Some health and social care professionals may feel uncomfortable about raising end of life in discussion. You can help to give them 'permission' to talk about the subject by asking questions, which then allows you to explore the available options for health care and/or social care.

See Section 3: Difficult conversations with professionals.

- Health and social care professionals can also contact our helpline, MND Connect, for guidance and information.

See Section 15: Help from the MND Association.

- Many different health and social care professionals may be involved in your care. It can be helpful to have one identified professional, such as a specialist nurse or MND coordinator, who can help act as a link between services on your behalf.

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 2: *What is likely to happen?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 1B: Information about MND or Kennedy's disease in other languages or Braille
- 3A: MND care centres and networks
- 6A: Physiotherapy
- 6B: Complementary therapies
- 7A: Swallowing difficulties
- 7B: Tube feeding
- 7C: Speech and communication support
- 8A to 8E: our sheets on breathing with MND, ventilation support and withdrawal
- 9A to 9C: our range of sheets on thinking and emotions in MND
- 10A to 10G: our range of sheets on benefits, social care and NHS Continuing Healthcare
- 11C: Equipment and wheelchairs
- 11D: Managing fatigue
- 14A: Advance Decision to Refuse Treatment (ADRT)

From our other publications:

What I should expect from my care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Understanding My Needs a write-on tool to enable you to record basic notes about your needs and how you would like to be cared for, if admitted to hospital or a hospice.

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

MND Alert Wristband to wear at all times, to let hospital and emergency staff know you have MND and may be at risk with oxygen.

Eating and drinking with motor neurone disease a guide including easy-swallow recipes and information about nutrition with MND.

Caring and MND support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

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

See Section 15: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at: <http://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

myTube website:

See this site for further information and video content about tube feeding: www.mytube.mymnd.org.uk Developed by SITraN – the Sheffield Institute for Translational Neuroscience.

7: Discussions with family and children

This section explores how to approach difficult conversations with those close to you to help everyone feel prepared and aware of your preferences.



“ The problem is that other people don’t want to mention end of life at all. My family can’t take it in and don’t want to talk about MND. It’s like, ‘If you don’t talk about it, it won’t happen’. Even the neurologist struggles to talk about it.”

Health and social care professionals have a duty of care to answer your questions about end of life and explain your options. This enables you to make informed choices and ensure that your needs, wishes and preferences will be respected.

This does not mean that asking those questions is easy.

See Section 3: Difficult conversations with professionals.

Talking to your family about death and dying can be even more difficult.

“ No one knew what to say and it was easier to say nothing, but that was worse. It felt like the elephant in the room and as though it was being brushed under the carpet.”

You may find yourself avoiding the subject, in case you upset other people. Your family, in turn, may avoid it in case they upset you. Discussing end of life with those close to you

means facing up to serious decisions, strong emotions and unwanted change. However, discussion can be very helpful both in practical and emotional terms. This section may help you find ways to start these conversations.

Once end of life decisions have been made, it can be a huge relief for everyone concerned. It means that everyone understands your wishes and preferences and you can concentrate on living again. It may bring families closer, even where there has been anger or friction in the past.

“ I think knowing the practical aspects of what is involved at end of life reduces fear. This will often be the first time that people are having to consider end of life issues due to a terminal illness. It certainly was in our family.”

Emotional reactions are to be expected when talking about such a challenging subject. These reactions can help release tension, sadness and grief. Showing that you are upset allows other people to express their feelings too. How other people react will vary greatly, depending on their relationship with you, their age and the way they respond to difficult situations.

Why do I need to talk about end of life with those close to me?

As end of life approaches, you may become unable to express your wishes. This can be difficult for your family, as they may need to make choices on your behalf.

“ Families often have decisions thrust upon them before they are prepared.”

However, if they feel confident that they know what you want, it may avoid additional distress, confusion and frustration.

You can use advance care planning to guide everyone involved in your care about how you want to be cared for at end of life. You can also provide written instructions about future withdrawal of treatments using an Advance Decision to Refuse Treatment form (ADRT). You can change your mind and renew the ADRT at any time. This may involve assessment of your mental capacity (your ability to make clear and reasoned decisions).

[See Section 9: Advance care planning and advance decisions, which includes information about mental capacity assessment.](#)

Planning ahead helps your family to be aware of your wishes and provides evidence to help health and social care professionals carry them out. It is important to talk about these decisions with your family to prepare them, even if this feels difficult.

“ These conversations are emotional because you know you’re going to distress the people you love. It also brings home the reality that you may not be here next month, next year, to do the things you want to do.”

If you create an ADRT, your family may be responsible for ensuring it is easily accessible for paramedics and hospital/hospice teams. This is a legal document and the original signed form must be available for professionals to be able to take action.

“ I have talked about all the end of life choices and issues with my wife and family. They are fully supportive of my proposed actions and are prepared to ensure all I’ve put in writing is carried out in the manner stated by me.”

Have these conversations when you feel ready to do so. This may take a little time, as a period of shock and adjustment is to be expected following diagnosis. However, we recommend talking about end of life as soon as you can. If not, complex discussions may become more difficult as the disease progresses. This is because:

- some people find their ability to speak and communicate is affected, including loss of gesture and facial expression
- MND can cause extreme fatigue, which may make it difficult to concentrate
- some people experience changes to thinking and reasoning.

[See Section 4: What to expect as the disease progresses.](#)

Depending on your circumstances, you may wish to inform other people about certain decisions.

“ I’ve talked to my work colleagues about it. I don’t want people to fawn over me, but I just want them to be aware of it so that we can put it to bed and get on with life.”

Putting your affairs in order and ensuring all financial and legal decisions have been made will also make things much easier for your family following your death. Talk about these aspects with them too, so they know what arrangements have been made and where to find documents and computer records (and passwords to access these).

“ We never ever talked about him dying... It would have helped so much... we didn't have the end of life experience that some people describe, ie with everything tied up. He used to say, 'if I think like that I'll give up.'”

See Section 8: *Putting affairs in order* and Section 10: *What happens after I die?*

How do I start conversations about end of life?

There are many ways to introduce a difficult conversation and you should choose a method that feels comfortable for you and those you need to talk to. Opening the discussion is usually the hardest part.

“The conversations we have generally come about accidentally or after a crisis.”

It might help to focus on one aspect at first and think about how you could lead into this. For example, you may want to help arrange your own funeral so that your wishes are respected. Bringing this into the conversation may feel challenging, but you can try a gentle approach first:

‘I heard my favourite song last night. I've always wanted to have this played at my funeral.’

From here you can see where the conversation goes. Asking questions may also give your family permission to open up about their thoughts.

Once you have had a conversation like this, it may feel easier to raise other concerns another time. Keeping the initial conversations short can help everyone feel more comfortable, without being overwhelmed. You can gradually tackle the more challenging areas as and when it feels right to do so.

“ My wife and I have talked... There are many difficult conversations that we've had to deal with, about all sorts of subjects. We've also had to deal with all sorts of other people and their responses to things, which can be difficult. One thing to note is that we're all individual. No two people will handle these conversations in the same way.”

You may also find it helpful to:

- set a time to talk specifically about end of life so everyone feels ready and focused
 - try to pick a quiet time to ensure that you won't be disturbed by anything else
 - share this guide or this section of the guide with your family first, to help them prepare
 - make a quick note of the main subjects you would like to discuss, so they know what to expect
 - talk to different people at different times, eg your main carer or partner will probably need more detail than a wider family member or a young child
- See later heading *Communicating about dying to children and young people.***
- start with general thoughts and explore in more detail as time goes on

- make sure you all have time to adjust to any big decisions – you don't have to make your choices all at once
- concentrate on just one area at a time, such as making a will, then deal with something else.

There may be cultural aspects that make it difficult to discuss end of life. If this is the case, it may be useful to ask a specialist in palliative care to help guide these conversations, perhaps with assistance from a community or faith leader.

“ In our Chinese culture there are speculations on this type of behaviour, eg in asking for a will, and my mother was angry. This is because it would seem that we are ushering my mother’s death to come closer and gain her wealth. But because we didn’t know her wishes, we didn’t know what to do. We got to know her wishes a lot later and they were harder to accomplish.”

End of life discussions do not always have to be about the harder decisions. Sometimes they may focus on creating memories and supporting each other.

“ There are ways to help you balance the emotion. You can watch films together, get out old family photos and remember happy times together, set up a tribute website, have a reunion of old friends and build memories to look back on for those who are left. Have interesting day trips out, make time to relax and have fun by going out, or hugging and holding hands which is comforting.”

What should we talk about?

You may wish to explore subjects such as:

- your future care needs and care planning
- what to do if you need emergency treatment
- contingency planning (eg what to do if your carer is unable to support you for any reason)
- options for treatment and withdrawal of treatments
- how to record an Advance Decision to Refuse Treatment (ADRT)
- putting your affairs in order
- organ and tissue donation
- what happens when you die
- funeral planning.

This guide will help you consider these and other issues. What becomes a priority for you will depend on your own views and family circumstances.

See also [Section 1: Why plan ahead?](#)

Support for your main carer

As your needs will increase due to the progressive nature of MND, the demands will grow for your main carer and others involved in your care. It cannot be emphasised enough how important it is for your carer to consider their own well-being. This may help to protect their own health, but also enable them to continue supporting you.

Accepting external support for some of your care can be beneficial. This may help to:

- provide a rest for your main carer, who may be under pressure from fatigue and worry
- maintain what was unique about close relationships before you had MND.

If your main carer is also your partner, it may cause strain between you, although some people find their relationship becomes stronger.

Your roles in the relationship are likely to change. Your partner may be new to the challenges of a caring role and may have to take on more of the physical tasks around the home.

If either of you are employed, you may have to consider whether to leave work as the care needs increase. Sense of purpose for both of you can be affected.

Social networks can grow smaller too, leading to a sense of isolation. You may also be concerned about intimacy, if this is important within your relationship.

See Further information at the end of Part 3: *What do those close to me need to know?* for publications on sex and relationships with MND, and work and MND.

Many carers try to hide their feelings to protect you and place their own needs as secondary. This can make it difficult to develop open communication, but to work as an effective team, this is very important.

“ It’s important that carers have the opportunity to talk about how to respond to distressing statements and how to discuss difficult issues. I was fortunate in that I had a lot of experience in palliative care so was more comfortable than most, but I wonder how other carers manage.”

Wherever possible, when you talk things through, try to include your carer's needs and fears as well as your own. Try to recognise when people close to you need to share their feelings and encourage this to help open conversation. This will enable understanding and help you develop better ways of coping as a team.

You carer may find it useful to see their GP or another health and social care professional to talk through any concerns. Discussing their

role as the carer may help them feel more ready for the challenges ahead. Be prepared that they may wish to do this alone. This may make it easier for them to talk openly at the appointment, without the worry of causing you distress. You can always discuss the main points of the conversation later to help your carer consider their own needs.

“ When you care for someone who you know is going to die and you go through their journey with MND with them, you should be spoken to honestly about what is going to happen.”

See Further information at the end of Part 3: *What do those close to me need to know?* for publications designed to support family carers and others involved in your care.

Talking about dying with children and young people

Many people find it difficult to talk about death and this can feel worse where children are involved. It is a natural desire to protect the young from distress, yet even young children notice far more than we realise. If they are left without clear explanations, their own imagination may fill in the gaps. They may think that they are to blame or become isolated and frightened.

We have developed information for children and young people to help you communicate with them about MND.

See Further information at the end of Part 3: *What do those close to me need to know?* for details about our publications to help children and young people.

You may be worried about getting upset, but this can give children and young people permission to release some of their own emotions. By talking about MND you are clearly demonstrating it is not a taboo subject, but one that is safe to discuss.

“ Although we were a close family, we didn’t talk much about what was happening or what might happen in the future. I wish we had talked more because a lot of my worries would have been dealt with.”

There is no need to give all the information at once.

How much and how often you should talk to children about MND and end of life will depend on their age and how quickly the disease is progressing. However, it is important to be clear in your explanations to avoid confusion or misunderstanding.

You may find the following helpful:

Children think differently

Children behave and react in a very different way to adults and it may seem as if they don’t appreciate the enormity of what is happening, or even care. This is not necessarily true, but you may find it bewildering.

Children tend to absorb information in bite-size pieces, then go back to what they were doing before the conversation took place. They may need to talk repeatedly about what has happened or ask questions about what is happening at inappropriate times. This may have an impact on how you feel, but it is natural and just a child’s way of dealing with events.

Helping children to understand

When discussing sensitive things with children, use language they understand. Words that we use as adults may have a different meaning to a child.

For example, a young child might interpret ‘heart attack’ as someone actually attacking someone’s heart, when all they need to hear is that the heart became poorly.

Where MND is concerned, it can help to explain that muscles are poorly, so that children understand why someone is changing and growing weaker.

You can start by talking about things the child will already have noticed. For example, if leg muscles are affected, explain how this will make it more difficult to walk. If facial muscles have been affected, explain how it may be difficult to smile, but this does not mean you are angry.

Using appropriate language is particularly important if a child has any kind of learning difficulty or problem processing information.

Be honest

Any questions that the child asks should be answered as truthfully as possible for their age and level of understanding. Skirting around an issue may confuse and cause anxiety for the child later on.

Try to explain what is happening during the course of the disease, so the child does not feel isolated. Keeping them involved allows them to say and do the things they need to as part of their own grieving. This may help them to develop ways to cope. For example, creating a memory book or box with the person who is dying can be a great way for both to capture moments that will provide comfort to the child in the future.

Help from others

People who are directly involved with the child should be told what is happening as soon as possible, so they can also offer support if needed, eg family members, teachers and family friends.

If teachers at the child’s school have information about MND and know how the disease is affecting your family, they can be a real source of support for the child, particularly in the later stages. You may wish to share publications about MND with them.

See Further information at the end of Part 3: *What do those close to me need to know?* for details about our publications to help children and young people, including a resource for professionals, such as teachers.

As they get older, children think in a more mature way, with a different level of understanding. Often, they will:

- seek information on their own and may know more than you realise, but still need to talk to you
- look up information on the internet and worry, as this is not always correct or relevant
- shoulder a heavy responsibility as a young carer
- feel torn between home and student life.

Try to encourage young people to maintain their links with the outside world. Reassure them that their friends and activities are essential in maintaining a balanced life.

Can anyone else help with these discussions?

You may find it helpful to explore your concerns with others who understand MND. This could include joining a local branch or group of the MND Association. Meeting other people in a similar situation and sharing experiences can help remove the feeling of isolation. Often groups hold informal support meetings for carers too.

Not everyone feels this is right for them at first, but you can join a branch or group at any point. You are likely to meet others who have considered their choices for end of life. This may provide a broader viewpoint on what is available and who to contact for objective guidance. However, it is important that any decisions you make feel right for you and your family.

If you have access to an Association visitor in your area, they can contact you by telephone or email, and they may be able to visit you at home. They can provide support and helpful information. If an Association visitor is not

available in your area, you may wish to contact our helpline, MND Connect, who can provide information and emotional support.

See Section 15: *Help from the MND Association.*

The MND Association online forum also provides a safe place for you to communicate with other people who are living with or affected by the disease at:

<http://forum.mndassociation.org> You can view forum conversations without joining if you prefer, which can still help to reduce feelings of isolation. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips.

Key points

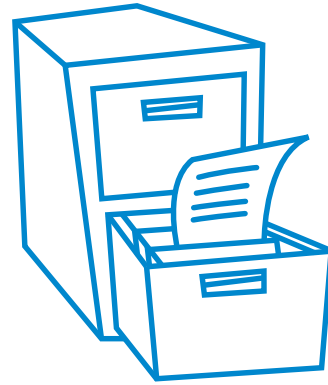
- There are specialist services and organisations that can help you, your family and those close to you to work through sensitive and difficult issues. Our MND Connect helpline can direct you to a wide range of support.

See Further information at the end of Part 3: *What do those close to me need to know?* for contact details.

- Try to find out what children think is happening. Leaving it to their imagination may be worse than you expect and you can help them to understand.
- Working together to keep things as open and positive as possible, can help to improve quality of life for the whole family.
- If your speech and communication are affected by MND, members of your family are likely to be able to understand you more easily than people who are not used to communicating with you. If you have discussed your wishes, needs and preferences, this will help them interpret for you in the later stages.

8: Putting affairs in order

This section provides guidance about financial and legal matters to ensure your affairs are in order.



Please note that the information in this section does not represent legal advice. All efforts are made to ensure accuracy at time of going to print, but details can change between revision dates. It is provided as an overview of what to consider and we recommend that you seek qualified legal and financial guidance in all matters.

“ Discussing and facing the financial and practical arrangements including the house, wills and funeral is important for my wife’s peace of mind.”

As you approach end of life, it is important to consider your financial, legal and practical arrangements. This can feel emotionally challenging as it underlines the finality of what lies ahead. However, planning ahead can help ensure that:

- you receive appropriate care as your needs increase
- your estate is handled in the way you would wish when you die
- those close to you have access to any advance care plans and advance decisions, so they can support you if you become unable to communicate your choices
- those close to you have access to important documents, records and accounts, so they can administer your affairs in the simplest way following your death
- your dependants are supported in the way you would prefer.

A summary table towards the end of the section provides a simple checklist of what to consider.

Planning is equally important if you do not have an immediate family circle, to ensure that health and social care professionals are aware of your wishes.

“ Being single and living with MND creates unique issues about accommodation, finance, transport, coping with life as you lose the ability to speak, walk, etc.”

Providing access to records

Ensure other people can find essential details when needed.

Gather all important documents and records: keep these in one secure place for ease of access during your care and in the event of your death. You may decide to give access to your main carer, partner, relatives or close friends, depending on your personal circumstances, care needs and who you name as executor(s) in your will.

List all main contacts and passwords: important contact details will be needed after your death, eg for your bank, insurance companies, etc. Add passwords and filenames for computer access if relevant, but make sure these notes are kept secure.

Provide written permission: your main carer will find it easier to talk to health and social care professionals on your behalf if they have your written consent to discuss your medical records.

Making a will

A will lets you leave instructions about what will happen to your money, property and possessions (known as your estate), in the event of your death. A simple will is not usually expensive and could save your family costs in legal fees.

“ I don't want to mope about thinking about things that I can't do. It's nice to do the practical things, eg making a will. That's something you can do and tick off the list, if you like...It makes me feel in control.”

Dying without a will

If you die without a will (called 'dying intestate'), the law decides what happens to your estate and those close to you may not receive the share you would have wished.

For example:

- you may want your estate to pass to close friends or charities, but without a will it could pass to distant relatives instead
- you may have children from a previous relationship who you would like to inherit something, but if you remarried and do not have a will, everything may go to your current spouse
- if you are neither married or in a civil partnership, and your bank accounts and home are in your sole name, your partner

will have no entitlement without a will, even if you live with them. In this instance, they may no longer have the right to live in your property after you die, or it may cost a great deal in legal fees to challenge how the estate is distributed.

Can I write my own will?

You can write your own will, but this is a legal document and needs to be worded correctly to be valid. Assistance from a qualified solicitor or reputable will-writing company is generally recommended, particularly if you:

- have complex finances
- need to provide for someone who is unable to make decisions (known as lacking mental capacity)
- need to provide for someone under 18 years of age
- have your own business
- have overseas finance or property
- share a property with someone who is not your husband, wife or civil partner
- have family members who may challenge your will, eg children from another marriage.

Search for *making a will* on the government online service www.gov.uk to find out more.

What needs to be included in a will?

Your will needs to include:

- who you want to benefit (known as beneficiaries) and the specific items or amounts you want them to receive
- who gets anything else that is left (known as the residue)
- who should benefit if the people you have named to receive items or amounts die before you do
- who you wish to appoint as guardians for any children under 18
- who is going to sort out your estate and carry out your wishes after your death, known as your executor (you can have more than one executor if required).

Your will must be signed and dated by two witnesses to your own signature. These witnesses cannot benefit from the will and must not be related to you or anyone else who benefits.

Your executor can be a relative or friend. They will have a legal responsibility to ensure your estate is distributed as instructed in your will. This can take a long time, particularly if a property needs to be sold, so you must ask first if they are prepared to accept this task. If your estate is likely to be complex, your executor may wish to appoint a legal professional to assist them after your death.

Unless you appoint a professional executor (which could be expensive), your executor will only be able to claim direct expenses from your estate. However, you can leave your executor items or amounts in the will if you wish.

When you have completed your will, keep it safe and secure, but ensure your executor can access it easily after your death, including passwords for any related computer records.

Can I change my will?

You can update your existing will, with an official alteration (called a codicil), or you can change your will at any time by making a new one. The new will should state that it revokes (officially cancels) all previous wills and codicils, and you should destroy your old will.

If you marry or enter a civil partnership, this makes any existing will invalid unless the will has been written to take the new relationship into account. A divorce does not invalidate a will, but following the decree absolute, a divorced partner cannot act as executor or benefit in any way. Should you wish to leave them something, you need to write a new will.

Can my will be challenged?

Your will can be challenged after you die, usually because:

- someone feels they have the right to make a claim, or a larger claim, against your estate
- someone thinks you lacked the ability to make decisions when it was written (known as mental capacity). For example, they believe that you had dementia or that medication was affecting your ability to make reasoned choices.

[See Section 9: Advance care planning and advance decisions for details about mental capacity and Power of Attorney.](#)

Can I make gifts to people before I die?

Some gifts made to others during your lifetime could be subject to inheritance tax after your death.

Inheritance tax is a tax charged to your estate when it passes a certain value. You can find out more from the Probate and Inheritance Tax Helpline: 0300 123 1072.

Your finances at end of life

As you approach end of life with MND, you are likely to need increasing care and support. This means you will need assistance to manage your finances. You may also wish to ensure that all your financial affairs can be easily dealt with following your death.

“ He wanted to make sure that everything was set up and that things were in order. That is one advantage of MND, that it gives you time to sort stuff out. He used to sit me down and we would look at spreadsheets together. I found this really hard because I knew what it represented, but that was his way of facing it.”

Access to bank accounts

If you have someone you trust to help you manage your finances, they will need to access your bank account. Ask your bank for advice, as there are various ways this can be done. The following options provide an overview.

Create a joint account: this may be helpful if your partner needs access to joint funds. A joint account will transfer to the other person's name after you die. Bear in mind that if the joint account is overdrawn when you die, the other person will be responsible for this debt. There is also a chance that if one of you is unable to make or communicate decisions (known as lacking mental capacity), the bank may freeze the account which means the other person cannot access the funds.

Third party mandate: you can write to your bank to allow someone to temporarily operate a bank account for you. This usually requires filling in a form, often called a third party mandate. You must be able to make this decision yourself and authorise the form. This is better than providing them with your account details and passwords, to prevent any risk of them being accused of fraud.

Transfer benefits to another account: you can arrange for benefits to be paid into someone else's account, so they can access the money for you. You must be able to make this decision yourself and authorise the form.

If you have a sole account, no-one will be able to access this after you die as the account will be frozen by the bank until your estate has been administered. And remaining funds or debt linked to the account will be counted as part of your estate.

See the heading *Administering your estate and probate* in Section 10: *What happens after I die?*

You can also arrange for someone to have Lasting Power of Attorney to manage your finances in case you either become unable to do this or unable to make decisions on your own behalf. In Northern Ireland this is called Enduring Power of Attorney.

See the heading *Do I need someone to act on my behalf?* in Section 9: *Advance care planning and advance decisions.*

What happens to any debts?

Your debts have to be paid from the proceeds of your estate, as administered by the executor of the will. You should investigate all debts, including any outstanding mortgage on your home, to find out what will happen after you die and whether your spouse or partner will still be responsible for payment.

If there is not enough money in the estate to pay all the debts, and you owned property (eg your own home), this may be at risk. People who are owed money from the estate (known as creditors) may agree to place a charge against a property, which means they will be repaid when the property is sold at a future time. However, some may try to force the sale. If you are worried this might occur, seek advice from a debt counselling agency.

What else will my executor or family need to know?

In addition to bank account access, you may wish to list details for the following. These will help your executor when sorting out the estate. They will also help your partner, spouse or close family to continue budgeting and managing the household:

- income and tax records
- any benefits or pensions that you claim, including private pensions
- household, vehicle or expensive item insurances
- health and general life insurances
- mortgage details and any life insurance policy to cover the mortgage
- investments, stocks and shares
- regular bills, such as water, gas, electricity and telephone
- annual bills, such as TV licences

- details for service companies, such as window cleaning or boiler servicing
- car records, such as the previous MOT certificate and registration
- paperwork if you have a vehicle through the Motability scheme
- hire purchase or credit agreements
- paperwork for any loans
- trust funds, grants or charitable funding
- membership fees and subscriptions.

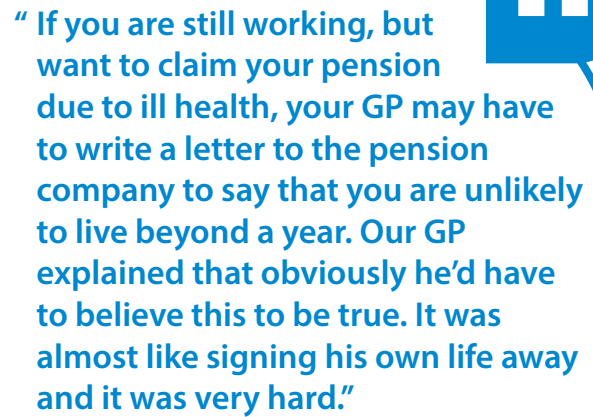
See also Section 10: *What happens after I die?*

You may wish to sell certain investments or cancel agreements that no longer feel appropriate (where feasible). Try to get qualified independent financial advice before making any major financial decisions, as there can be unexpected consequences.

For example, taking a lump sum from your pension may affect your eligibility for certain benefits where income and savings are taken into consideration. If you have a private pension, it may provide benefits for your partner should you die before retirement age.

See Further information at the end of Part 3: *What do those close to me need to know? for a list of information sheets on financial support and employment.*

If you are employed, it may be worth considering early retirement, but it can impact on the benefits you will be allowed to claim. You may also want to check if your employer runs a death in service scheme, as this may benefit your family after your death. Explore all of these options carefully before making decisions.



“ If you are still working, but want to claim your pension due to ill health, your GP may have to write a letter to the pension company to say that you are unlikely to live beyond a year. Our GP explained that obviously he’d have to believe this to be true. It was almost like signing his own life away and it was very hard.”

It can be very difficult to get health and insurance cover following diagnosis. Try not to depend on existing insurances for financial back-up until you know exactly what cover will or will not be provided. Ask the insurance companies to explain this to you.

If you have any questions about how to manage your finances towards end of life, you may wish to contact our helpline, MND Connect. They can provide information or direct you to specialist help.

See Further information at the end of Part 3: *What do those close to me need to know? for contact details.*

Support for dependents

As you approach end of life, thinking about how your dependents will manage in the future can cause great anxiety. It is important to discuss the options with your family and, if necessary, with social care professionals and legal representatives.

If you have adult dependents who require your financial or personal support, talk to your local adult social care service through your local authority (or in Northern Ireland, through your local health and social care trust).

If the dependent person lives in a different area, you may also need to approach their own adult social care service. Social workers or care managers will be able to provide guidance on available care options and provide an assessment if required.

“ My mother’s got dementia. We’ve just helped her to move into a care home. I have MND, but I’ve been more concerned about her than anyone else.”

If you have children, and you know who you would like as guardians, ask them if they would be prepared to accept this responsibility. If they agree, you can name them as guardians in your will.

You should consider this even if the other parent is going to continue looking after your children in the event of your death, in case they also die before the children reach 18. Should this happen, and guardians have not been appointed, the courts will decide who looks after your children.

See earlier heading in this section, *Making a will.*

Who will look after my pets?

If you have pets, you may need to plan for them too. A family member or friend may be willing to take over their care, but this needs to be discussed in advance.

It is worth contacting organisations such as The Cinnamon Trust: www.cinnamon.org.uk. They may be able to arrange alternative care for a temporary period, should you need to go into hospital, or find a new home for your pet at a time that feels right for you (or following your death). If an adoptive owner cannot be found, local rescue centres can usually help.

See Section 16 *Useful organisations for full contact details.*

Personal needs

Discussion with health and social care professionals, particularly those involved in specialist palliative care services, will help you to make informed choices about how you would like to be supported as the disease progresses.

This guide focuses on end of life decisions to help you ask searching questions and access the best possible care that feels right for you.

These discussions may help you plan ahead with more confidence. You can make people aware of your wishes by using:

- a document called an Advance Care Plan, which lets you record preferences about your ongoing care (this helps guide the professionals who support you)
- an Advance Decision to Refuse Treatment (ADRT), which informs professionals of the specific circumstances in which you would want life-sustaining treatments to be refused or withdrawn
- a Lasting Power of Attorney (LPA) in England and Wales, or Enduring Power of Attorney (EPA) in Northern Ireland, which allows a trusted relative or friend to make decisions on your behalf

See Section 9: *Advance care planning and advance decisions for more detail on how to make these arrangements.*

It is important to tell everyone involved, including close family and friends, health and social care professionals and emergency medical teams about these records. Also ensure these documents are accessible, or your wishes may not be carried out.

You may also want to consider the following:

- whether you would like to donate your organs or tissue for transplant or research purposes

See Section 12: *Organ and tissue donation.*

- a funeral savings plan or pre-paid funeral, but seek advice from the Funeral Planning Authority:
<http://funeralplanningauthority.co.uk>

See Section 16: *Useful organisations for full contact details.*

- what you would like to happen at your funeral.

See Section 10: *What happens after I die? for more details about funerals.*

“ We’ve met with a funeral director and discussed how we’d like my funeral. I wanted to get all this sorted so my wife didn’t have to deal with it...we’ve ‘parked’ this so that we don’t have to worry about it. Once you’ve thought about these things you can get on with living.”

Roles and relationships

Roles change when dealing with a progressive illness like MND and your partner may have to take on tasks that are unfamiliar. It may be useful to tell your partner about everyday activities you have always taken responsibility for, such as cooking, how appliances and the heating system work, dates for family birthdays or seasonal gardening tasks.

This can also be a time for resolving any difficulties in family relationships and thinking about how you would like to be remembered. You can do this face to face, but also through letters that you can leave for others, audio and video recordings, scrapbooks, memory boxes and sentimental items.

See Section 7: Discussions with family and children.

Memories are not just about recording the past, but about the time you have now. Your life will continue to change as you adjust to the progression of the disease, but many people find that approaching end of life enables more focus on their immediate circle of family and friends.

“ He wanted to concentrate on living, making plans for each day and living each day as well as the limitations allowed. This involved spending as much time as possible with family and friends.”

Digital legacy

Your digital legacy refers to any online records you leave in your name. You may wish to think about:

- if online access to banking or financial accounts will need cancelling or administration and how to inform the executors of your will about this
- whether any digital items with financial value need to be included in your will, such as ebooks you have authored
- whether your right to pass on anything you ‘own’ online depends on the terms and conditions of the organisation where it was sourced or is now stored
- what happens to any digital records that have emotional value rather than financial worth, such as photographs
- what happens to any social media accounts you run (you may wish to provide passwords to someone you trust for guardianship, as the content may be comforting for family and friends).

For more detail about digital legacies and what to consider, see the Digital Legacy Association at:

<https://digitallegacyassociation.org/for-the-public>

Summary of things to consider

The following table provides a checklist of things to consider when putting your affairs in order, with references to other useful sections in this guide.

See Further information at the end of Part 3: What do those close to me need to know? for a list of publications relevant to the subjects covered in this section for a list of relevant publications.

	Things to consider	Useful sections
Legal	<ul style="list-style-type: none"> • Select a legal professional for assistance with legal documents, such as your will. • Make a will. • Keep all important documents, certificates and records in one safe place. • Note where to find important documents, with a list of key contacts. Give these instructions to your main carer, partner, relative or friend. • If required, arrange for Power of Attorney for your chosen representative. 	<p>9: <i>Advance care planning and advance decisions</i></p>
Care	<ul style="list-style-type: none"> • Provide written consent for health and social care professionals to discuss your medical history with your main carer, partner, relative or friend. • Ensure you have your wishes, needs and preferences for future care recorded on an Advance Care Plan (ACP). • Record any advance decisions about refusal or withdrawal of treatments on an Advance Decision to Refuse Treatment (ADRT) form. • Talk through end of life planning with your health and social care team. • Make any arrangements for organ or tissue donation, if wished. 	<p>3: <i>Difficult conversations with professionals</i></p> <p>4: <i>What to expect as the disease progresses</i></p> <p>6: <i>What care is available?</i></p> <p>9: <i>Advance care planning and advance decisions</i></p> <p>12: <i>Organ and tissue donation</i></p>
Dependants	<ul style="list-style-type: none"> • Arrange care services for adult dependants, if they need support during your end of life care or after your death. • Make arrangements for guardianship for children under 16 (even if you have a partner, in case both of you die before the child/children become adult). 	<p>7: <i>Discussions with family and children</i></p> <p>11: <i>Inherited MND and genetic counselling</i></p>

	Things to consider	Useful sections
Financial	<ul style="list-style-type: none"> • Consider who will help manage your bank account, credit cards or safety deposit box, if needed, and how this will be done. • Find out what will happen to any outstanding mortgage on your home or to any debts that you owe when you die. • Keep all financial and tax records in one safe place, including sources of income such as pensions, shares, insurance and benefits. • Note where to find important documents, with a list of key contacts. Give these instructions to your main carer, partner, relative or friend. 	<p>10: <i>What happens after I die?</i></p> <p>15: <i>Help from the MND Association</i></p> <p>16: <i>Useful organisations</i></p>
Personal	<ul style="list-style-type: none"> • If you wish, decide how you would like to be remembered, through letters, recordings, video or keepsakes. • Discuss any wishes you may have about your funeral with family and friends. • Gather contact details for wider family and friends that you would like to be informed about your death. • Let people know about any arrangements for organ or tissue donation, if planned. 	<p>7: <i>Discussions with family and children</i></p> <p>9: <i>Advance care planning and advance decisions</i></p> <p>10: <i>What happens after I die?</i></p> <p>12: <i>Organ and tissue donation</i></p>
General	<ul style="list-style-type: none"> • Leave instructions about how and when to do tasks that have always been your responsibility, eg car services and MOTs, insurance renewals or how to operate household appliances. • Inform anyone who needs to help manage your digital legacy - in other words, any records, documents, resources, media or presence you have online (see earlier text in this section for details). 	<p>15: <i>Help from the MND Association</i></p> <p>16: <i>Useful organisations</i></p>

Key points

- Without a will, your estate may not be administered in the way you would prefer. Those you wish to benefit may not be entitled to receive gifts or funds.
- Once you have made your plans, try to keep all important records together in a secure place where they can be easily found by those supporting you.
- Provide a trusted person with passwords to computer records you may have, so they can access these to assist you or manage your estate after your death.

9: Advance care planning and advance decisions



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

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

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

Planning for urgent situations

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

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

Who can help answer these questions?

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

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

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

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

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

Can I do anything else to plan ahead for emergencies?

You may find the following useful:

MND Alert Wristband:

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

MND Alert Card:

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

Understanding My Needs:

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

Carer's Emergency Card:

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

Message in a Bottle:

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

MedicAlert:

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

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

Make important documents easy to find:

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

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

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

Advance care planning

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

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

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

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

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

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

Location of care

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

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

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

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

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

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

How do I record my plans?

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

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

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

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

NHS England, End of Life Care

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

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

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

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

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

Advance Decision to Refuse Treatment

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

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

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

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

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

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

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

Do I have to do this?

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

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

However, you might have a different view:

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

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

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

What do I need to include in my ADRT?

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

Your ADRT must be in writing and include the following:

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

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

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

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

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

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

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

What decisions can be included in an ADRT?

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

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

Example:

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

[See Section 4: What to expect as the disease progresses for details about interventions and withdrawals in the later stages of MND.](#)

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

What decisions *cannot* be included in an ADRT?

An ADRT cannot be used to:

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

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

What happens if I change my mind?

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

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

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

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

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

Who needs to know about my ADRT?

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

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

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

What does DNACPR mean?

DNACPR in full means: Do Not Attempt Cardiopulmonary Resuscitation.

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

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

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

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

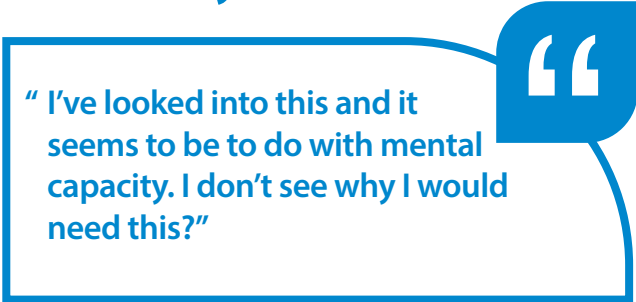
Will the DNACPR always apply?

The DNACPR can be suspended or cancelled as circumstances change. For example, it could be suspended if you need surgery, as CPR may be appropriate in the unlikely event that your heart or breathing stop during that short time.

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

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

Do I need anyone to act on my behalf?



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

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

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

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

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

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

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

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

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

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

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

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

Lasting Power of Attorney (LPA) – England and Wales

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

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

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

There are two types of Lasting Power of Attorney:

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

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

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

Enduring Power of Attorney (EPA) – Northern Ireland

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

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

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

10: What happens after I die?



This section looks at how you can influence what happens after you die and provides guidance for those close to you.

Please be aware that the following pages contain sensitive information. You may want to shape the way things happen after your death, but if not, your family, carer, close friends or executors of your will may find this section helpful.

“ 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.”

See end of this section for a *Summary of tasks* that need to happen following a death.

Informing other people

There are three main groups of people that should be informed when you die:

- family and friends
- work colleagues (if you were still employed or had been recently employed)
- relevant organisations.

You can help make this easier for those close to you by listing who should be informed, with contact details from your address book, computer or telephone.

Those close to you may find it emotionally difficult to tell wider family and friends that you have died. It may help to ask trusted people to assist, as and when the time comes, and later to help send funeral details. They can also help inform relevant organisations.

It is also useful to group together details for organisations that need to be contacted. These generally include:

Health and social care contacts:

such as your GP, your dentist and any specialists that you may have seen on a regular basis for MND. If you die in hospital or a hospice, they may be informed through their systems.

Government and local authority contacts:

to stop any benefits, pension payments and/or social care services that you may have received. If you live in England and Wales, you may find the Tell Us Once service useful to avoid repetition, which is available through your local council register office or online through www.gov.uk/tell-us-once. They will then make contact with your executor, partner or relatives as required to update all records.

Financial contacts:

such as your bank, or insurance or investment companies. It is important for your executor or family to inform these contacts as soon as possible, as this can help prevent someone using your stolen identity. Once these organisations know that you have died, they will usually give your executors or relatives time to sort out your affairs, even if debts are involved.

Legal contacts:

such as your solicitor, who may be familiar with your estate. However, unless you have stated that you want your executor or family to use a preferred legal professional (perhaps where your estate is complex), they may find it worthwhile to compare costs, as legal fees can vary widely.

Service contacts:

where personal and household payments may need to be cancelled or amended. For example, house insurance may need to be transferred to another name or it may no longer be valid.

[See Section 8: Putting affairs in order.](#)

Funeral arrangements

Attending a funeral enables those close to you to acknowledge what has happened. This can help them say goodbye and begin to adjust.

You may wish to leave instructions about the way you want your funeral to be arranged. You may have preferences due to:

- cultural requirements, where religious rites or other rituals need to be observed
- strong beliefs or views about what you would or would not want to happen at your funeral
- a wish for particular songs, memories and messages to be shared.

However you may prefer not to be involved in these arrangements.

“ Regarding funeral arrangements, I couldn’t care less! I’ve made provision to pay for the funeral and buy a few beers, but the details are for someone else to think about.”

The choice is yours and this should be respected, but it can help to let those close to you know your main preferences, which may be influenced by your religion, culture or beliefs.

For example:

- if you wish to be cremated or buried (and if so, where?)
- if you want a religious ceremony or not.

“ I’ve thought about where I’ll be. It makes me think about the spiritual aspect.”

[See Section 2: Emotional and psychological support, which includes content about spiritual and religious support.](#)

If you do want to provide specific instructions, you may find that your family and friends find this difficult to discuss.

“ I heard a piece of music years ago and decided that it was what I wanted to be playing when my coffin was carried in. Planning a funeral is really important to me but it’s amazing how many people won’t talk about it.”

Having open discussions with your family about your funeral can be very positive, so they know your wishes.

[See Section 7: Discussions with family and children.](#)

However, if this proves to be difficult, you can instruct a funeral director in advance who will help guide your family and friends when the time comes.

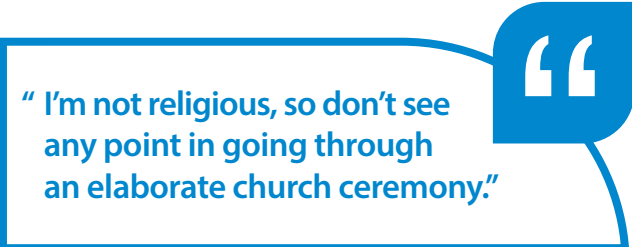
“ I’ve chosen everything for my funeral, the music and where my ashes will be scattered. It’s all with the undertakers. I did all this myself because I knew what I wanted, and to take it out of the hands of my daughter.”

You can also add funeral instructions in your will. There is no legal obligation for relatives to follow these instructions, but your executors are responsible for seeing that the instructions in your will are carried out, as far as is reasonably possible. There may be a financial limitation or another reason why something cannot be carried out, but leaving clear details about your wishes may help relieve other people of some of the decision-making.

What type of funeral can I have?

Funerals can be arranged in many ways. The main types are:

- a traditional religious ceremony according to your faith, usually conducted by a local faith leader
- a civil funeral (which may include some religious content, such as hymns and prayers), usually conducted by a civil celebrant
- a funeral with no religious content, usually conducted by a humanist celebrant.



“ I’m not religious, so don’t see any point in going through an elaborate church ceremony.”

The funeral service can be formal or informal, as directed by the person who is making the arrangements and your instructions if you have left written details about your preferences.

You may wish to choose a funeral director to help with arrangements, or a funeral specialist if particular cultural or religious rites need to be observed. If you don’t already know who will conduct your funeral, your funeral director can advise about local faith leaders and civil or humanist celebrants.

Try to select a funeral director who belongs to a professional association, such as the National Association of Funeral Directors (NAFD): <http://nafd.org.uk> or the Society of Allied and Independent Funeral Directors

(SAIF): <http://saif.org.uk>, who use codes of practice and complaints procedures. If your family plan to carry out the funeral themselves with little or no help from a funeral director, the Natural Death Centre can assist: www.naturaldeath.org.uk

See Section 16: Useful organisations for full contact details.

The funeral director or specialist organisation will guide the entire process and will usually book any additional professional services that are required. Your wishes and those of your family will be incorporated into the planning wherever feasible and your family will be asked to provide details about you and your history should the service include a memorial speech.

It is usually left to the family to arrange any reception and catering following the funeral, although some funeral directors may be happy to help organise this.

Paying for the funeral

Essential funeral costs can be charged to your estate, but if the proceeds from your estate do not meet the costs, whoever arranges the funeral is still expected to pay the final bill.

Although your bank account is likely to be frozen after your death (until your estate has been sorted), most banks will release money to cover funeral costs, as long as there is enough in the account. The bank will require a formal invoice and will make the payment directly to the funeral director. If the bank is willing to do this, your family or partner does not have to pay up front and then wait until the estate is administered to be repaid.

If your family are likely to need financial help with the funeral, there are benefit payments available, as long as they qualify. A one-off funeral payment may be provided, although this is unlikely to cover the full cost of the funeral. Your partner or spouse may also be eligible for other bereavement benefits.

Search for funeral payment or bereavement benefits at www.gov.uk for latest online government information.

It is important to note that any reception arrangements and refreshments provided after the funeral are not considered to be essential funeral expenses and therefore cannot be charged to the estate.

Funerals can be very expensive and sometimes in unexpected ways. For example, you may wish to have a cardboard coffin thinking it will be less expensive, but it can cost more than a wooden coffin.

You may wish to ask a funeral director about expected costs. They will also be able to tell you about saving plans and pre-paid funeral plans, which may be a way to offset the cost for your relatives. Seek advice from the Funeral Planning Authority:

www.funeralplanningauthority.com

See Section 16: Useful organisations for full contact details.

It is important that your family or executors do not sign any paperwork with a funeral director until they are sure they want to employ their services. If they do sign before this, they may have signed a legal contract and be liable for payment.

Administering your estate and probate

If you have any bank accounts, savings, property or other assets when you die, this is known as your estate. This needs to be administered, which means giving items or amounts from your estate to those who are entitled (your beneficiaries). This is decided in your will or, in the absence of a will, by law (under the rules of intestacy).

If you live in Northern Ireland, the process used to administer someone's estate is very similar to that in England and Wales, but there will be some differences. You can find out more from the NI Direct website:

www.nidirect.gov.uk/what-is-probate

See Section 16: Useful organisations for contact details.

What is probate?

Probate is a court order that proves the validity of your will and allows your executor or executors to administer your estate according to your will.

You may find the following definitions useful:

Grant of probate: this is the document provided by the courts to your executor so they can prove they have the right to deal with your estate through probate, when approaching organisations about your funds or property.

Letters of administration: if you have not written a will, you will not have a named executor. In this instance, a personal representative will be appointed by the courts to administer your estate according to the law. This person is usually your spouse or civil partner (or children if you are single), who will be provided with letters of administration as proof of their authority.

Grant of representation: this is a general term used to refer to either a grant of probate or letters of administration, whichever might apply.

A grant of representation may not be required if your estate is simple and low in value. In these cases financial organisations, such as banks and insurance companies, will help guide your executor or family to release any funds.

A grant of representation for probate is likely if:

- the value of your estate or an account reaches a certain limit (financial organisations may set different limits at which they would request probate for release of funds)
- you own a property in your sole name
- you own a joint property but wish for part or all of your share to pass to someone else, eg a child.

There may be other circumstances that mean probate is necessary and depending on the complexity of your estate, your executor or family may need to ask a legal professional for assistance.

How is an estate administered?

The following provides a brief and simple overview. The full process depends on your estate and the instructions you leave in your will. Your executor or personal representative should seek legal advice if in any doubt.

Whoever administers your estate will need to:

- inform people about your death who hold any of your assets, such as banks where you have an account
- inform people about your death if you owe them money (known as creditors)
- work out how much your estate is worth at the date of your death
- pay inheritance tax if appropriate
- apply for the grant of representation
- place statutory notices (usually small newspaper adverts) to inform any unknown creditors, should they need to make a claim against your estate. If in doubt, ask a legal professional for advice (this is not mandatory, but will protect your executor or personal representative against late claims, for which they could become liable themselves if they do not place these notices)
- gather all funds and items to be distributed, including the sale of property if required (known as collecting assets)
- pay any debts
- prepare a set of accounts for the estate
- distribute the estate to beneficiaries (those named in your will or, if there is no will, as decided by law).

Where it is recognised that your estate will not be able to pay its debts, even with the sale of any property, personal representatives should seek legal advice before taking any action. Making a mistake could result in them being liable for your outstanding debts.

Your executor or representative may also want to contact the Probate and Inheritance Tax helpline with any queries: **0300 123 1072**. Or they can search for probate and inheritance on the GOV.UK government information website at: www.gov.uk for details about the grant of representation, probate and administering your estate.

See Section 16: *Useful organisations for details of other organisations that may be able to provide guidance.*

Bereavement support for family and friends

Everyone will have an individual response to their unique loss, depending on circumstances, background and emotional state. It is important to realise that grief can encompass many feelings and may feel irrational, but grief is personal and there is no right or wrong way to experience it.

You may be concerned about how your family and friends will cope with their grief when you die. It is normal for bereavement to feel very distressing and isolating, but with an incurable and life-shortening illness like MND, the grieving process usually begins in advance of the bereavement. This is known as anticipatory grief and may impact on the wellbeing of your family before and after your death.

Anticipatory grief can take its toll on health and wellbeing. Having to then deal with bereavement and the aftermath can be very tough. The progressive nature of the condition means that your main carer and family probably had to provide increasing support during the course of the disease and may have experienced multiple and difficult emotions through this period.

Pre-bereavement counselling may be available to help with the impact of anticipatory grief. If you feel this would help you or your family, ask your GP for advice on services. Sometimes a local hospice can also provide this type of support.

“ If you're a carer, be aware of the effect the death might have on your health. The shock of suddenly not being a carer and having to deal with certificates, registration, stopping pensions before more payments are credited, notifying family and friends, fielding the inevitable telephone calls and arranging a funeral can be very stressful.”

It may be worth encouraging your main carer (often your partner) to think about booking health check-ups, both now and in the future. These appointments can be useful during the challenges of the caring role, but are recommended following bereavement, as your carer may feel exhausted physically and emotionally.

“ The carer is the one left with all the memories and can shoulder a lot of guilt.”

Sometimes, a life-shortening condition can bring people closer together, providing time for reflection. It can help families to make up for past quarrels and opens up opportunities for everyone to share their feelings.

Carers and those close to you may also find it helpful to talk to someone else in confidence. Our helpline MND Connect can provide a listening ear and guidance, including details about organisations who provide bereavement support. They can also offer information about bereavement and funeral benefits, and returning to work if wished.

See *Further information* at the end of Part 3: *What do those close to me need to know?* for a list of publications that can support during bereavement or assist carers with their own wellbeing. Our publications for carers also provide guidance on employment options during care and returning to work after bereavement.

You may also find it helpful to contact your local branch or group of the MND Association. Where an Association visitor is available, they will usually continue to provide support during bereavement.

See *Further information* at the end of Part 3: *What do those close to me need to know?* for our helpline contact details and Section 16: *Useful organisations* for support, such as *Cruse Bereavement Care*.

Summary of tasks

The following table provides a checklist of what needs to happen following your death, when this needs to happen and who needs to do each task.

Task	When	Who
Death is confirmed or 'verified'	<p>As soon as practical after death. In hospital, staff may give your family time alone with you first.</p> <p>Should you die at home, your family or main carer should contact your GP as soon as they feel ready to do so. They do not have to call 999 (as well as the GP) where the death was expected.</p>	<p>A doctor can verify a death. A registered nurse with relevant training can also verify a death, where this was expected. To keep this as simple as possible, the doctor should have seen you within 14 days of death, so keeping in touch with your GP at end of life is important.</p> <p>The person who verifies death will usually disconnect any medical equipment.</p>
Organ and tissue donation	<p>It needs to happen as soon as possible after death, should circumstances allow. This may only be possible if you die in hospital.</p>	<p>If you have made arrangements for organ or tissue donation, those close to you need to know in advance, as well as relevant health and social care professionals.</p> <p>See Section 12: Organ and tissue donation for details.</p>
Your body is moved to a mortuary or a funeral director's premises (there may be cultural or religious requirements that influence this, particularly if you die at home or your body needs to remain at home for a period of time before the funeral).	<p>After death is confirmed and as soon as arrangements can be made.</p> <p>If your death has happened at the time expected, a GP may authorise a funeral director to move your body and visit to confirm death at the funeral director's premises.</p>	<p>By mortuary or funeral director staff. If at home, a member of your family will usually need to inform the funeral director. If your body is held in a hospital mortuary first, your family will be asked to appoint a funeral director and make arrangements for them to transfer your body to their chapel of rest.</p>

Task	When	Who
<p>Either the Medical Certificate of Cause of Death is provided, or the coroner investigates the death (depending on the circumstances).</p> <p>See Key points at the end of this section.</p>	<p>After death has been confirmed.</p>	<p>A doctor gives the completed certificate to your family or representative, or arrangements are made for investigation by the coroner.</p> <p>See Key points at the end of this section.</p> <p>Please note: other arrangements may be necessary if a coroner is involved for any reason, or an inquest is needed.</p>
<p>Registration of death</p>	<p>In England, Wales and Northern Ireland this must be done within five days of the death (it is a criminal offence not to register a death).</p> <p>An appointment needs to be made in advance, with the Registrar of Births, Deaths and Marriages. If possible, the person registering your death should take along your NHS medical card, National Insurance Number, birth and any marriage certificates, driving licence, passport, a Council Tax Bill and proof of address, such as a utility bill. If your spouse or civil partner has survived you, their National Insurance Number may also be required.</p>	<p>The Medical Certificate of Cause of Death must be taken to the Registrar by a close relative, someone present at the death, the person taking responsibility for the funeral or an administrator from the hospital.</p> <p>The registrar will provide the necessary documents to enable your funeral to proceed and your estate to be administered. The registrar will explain what each document is for to your relative or the person registering your death.</p> <p>Extra certified copies of the death certificate can be purchased by the person registering the death, as this document is likely to be needed several times during the administration of your estate.</p> <p>Search for 'register a death' at www.gov.uk for more details in England and Wales, or www.nidirect.gov.uk in Northern Ireland.</p>
<p>Arranging and holding the funeral</p>	<p>Usually within two weeks of death, but this may be influenced by cultural requirements or the need for investigation by the coroner (if necessary).</p> <p>See Key points at the end of this section.</p>	<p>Family and friends may wish to make their own arrangements, but this is usually done with the assistance of a funeral director.</p> <p>See earlier heading in this section, <i>What type of funeral can I have?</i></p>

Task	When	Who
<p>Informing health, government, financial, legal and service organisations</p> <p>See earlier heading in this section, <i>Informing other people.</i></p>	<p>As soon as possible to avoid problems with overpayment on bills or receiving income that may need to be repaid, eg stopping benefits and pensions that you were receiving.</p>	<p>This can be done by family or friends, or executors of your will. Some of these contacts may need to be made during the administration of your estate.</p> <p>See Section 8: <i>Putting affairs in order for more detail about making a will.</i></p>
<p>Claiming funeral and bereavement benefits</p>	<p>Within three months of your death.</p>	<p>If eligible, bereavement benefits only apply to your spouse or civil partner. Funeral payments can be claimed by close family or close friends if they are taking responsibility for the funeral, but may have to be repaid from your estate.</p> <p>See Further information at the end of Part 3: <i>What do those close to me need to know?</i> for details of Information sheet 10A: <i>Benefits and entitlements.</i></p>
<p>Administering the estate</p>	<p>This usually begins after the funeral, but can take time depending on the complexity of your affairs.</p> <p>See earlier heading in this section, <i>Administering your estate and probate.</i></p>	<p>Where you have a will, this will be done by your executors. Where there is no will, the law decides what happens to your estate.</p> <p>See Section 8: <i>Putting affairs in order for more detail about making a will</i></p>

Key points

- In most cases of MND, your death will not be referred to the Coroner or for post mortem. However, this may be necessary if the doctor is unable to issue the Medical Certificate of Cause of Death, eg he has not seen you for more than 14 days before your death or believes that someone else may have been involved in your death. It may also be necessary if you appear to have died from something unrelated to MND, which needs to be determined.

See also Section 12: Organ and tissue donation and Section 13: Suicide and assisted suicide.

- If your doctor is able to provide a Medical Certificate of Cause of Death immediately after your death, it can be a shock for your family or friends. It will be the first time they see your death confirmed in writing and it may help if they know to expect this.
- Try to get your affairs in order before you die, such as making a will. This will make the practical tasks after your death much simpler for those close to you, during a difficult and emotional time.

See Section 8: Putting affairs in order.

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 3: *What do those close to me need to know?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 1B: Information about MND or Kennedy's Disease in other languages or Braille
- 4A: Communicating about MND to children and young people
- 8C: Withdrawal of ventilation
- 9A to 9C: our range of sheets on thinking and emotions in MND
- 10A: Benefits and entitlements
- 10E: Work and MND
- 10G: Support for families with children
- 13A: Sex and relationships for people living with MND
- 13B: Sex and relationships for partners of people living with MND
- 14A: Advance Decisions to Refuse Treatment (ADRT)
- 14B: Bereavement support

From our research information sheet range:

- I: Tissue donation for motor neurone disease research

From our other publications:

Advance Decisions to Refuse Treatment (ADRT) pack which includes our ADRT information sheet, a sample completed ADRT form and a blank form to fill in, if you wish.

Understanding My Needs a write-on tool to enable you to record basic notes about your needs and how you would like to be cared for, if admitted to hospital or a hospice.

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

MND Alert Wristband a silicon alert band you can wear at all times, so that hospital and emergency staff are made aware you have MND and may be at risk with oxygen.

What I should expect from my care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Caring and MND support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

Caring and MND quick guide a small A5 booklet to help someone new to the caring role.

When someone close has MND - a workbook for children aged four to ten an activity book designed to help a trusted adult communicate with a child about MND and to help the child develop ways to cope with the impact.

So what is MND anyway? a resource for young people who are close to someone with MND, written with the help of young carers who have supported someone with the disease.

Supporting children and young people close to someone with MND a guide for teachers, social workers and other supporting professionals to help them better understand how MND can affect the whole family, and provide suitable assistance for younger members.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

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

See Section 15: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at: <http://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

11: Inherited MND and genetic counselling



This section provides guidance on how to explore whether you have a family history of MND and what to do should you wish to leave a genetic history for your current and future blood relatives.

As you approach end of life, you may find yourself making various legal and financial arrangements to assist your family in the future.

See Part 3: What do those close to me need to know?

As you put your affairs in order, you may think more widely about the future of your family and this could include thoughts about the impact of MND if you have a family history of the disease.

You may have questions about genetic counselling and genetic testing that you would like to explore. This section provides an overview of what to consider and how to access specialist advice.

What causes MND?

It is still not possible to give a clear answer about the precise causes of MND as each individual may be affected by a different combination of triggers. However, during consultations with your neurologist in the early stages, you may be asked about any family history of MND. You may also be asked if there is a family history of frontotemporal dementia, as this may indicate that MND could have been present, even if not diagnosed at the time. It is worth asking the consultant to discuss family history, as this may help determine if an inherited gene is one of the likely factors.

“ My father died of MND 25 years ago and his brother also died two months after of MND. When this happened I didn't know much about MND and was told it wasn't inherited. Due to this I wasn't worried and didn't imagine it would happen to me in the future, or even think about it again until it 'hit me!' ”

MND with no apparent family history:

Most cases of MND occur with no apparent family history of the disease, which is sometimes referred to as sporadic MND.

The precise causes in these instances are not yet known. Multiple genetic and environmental triggers are thought to be involved. The environmental triggers may be different for each individual, so there is no simple way of identifying what may have caused the onset of the disease.

In these cases, other family members are at no greater risk of MND than anyone else in the population.

MND where there is a family history:

In some cases, there is a family history and the role of genes is more significant. Where this occurs, the disease is caused by a mistake in the genetic code which can be passed down.

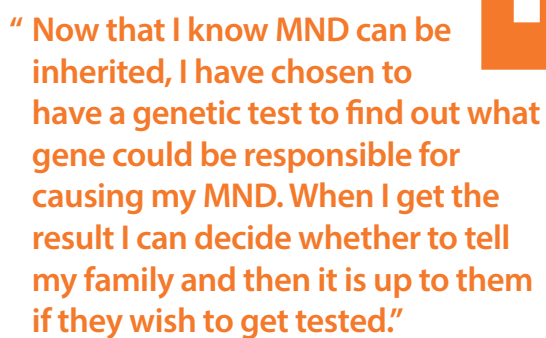
Even where this is the case, it is important to emphasise that other triggers may still be necessary for the disease to emerge.

If you are concerned about the possibility of a family history of MND and what this could mean for those close to you (in terms of inheriting the change in the genetic code), you may wish to seek genetic counselling.

Although sensitive to the emotional aspects of the situation, genetic counselling is not a form of psychotherapy. A genetic counsellor explains the facts as clearly as possible, and gives you accurate information on the implications for your family.

This will include information about options such as genetic testing, to help you make up your own mind if this is a choice you wish to make.

Some genetic testing is possible, but not everyone with a family history would benefit. Currently, testing is only available for some of the genes that play a part in inherited MND and results may not be conclusive.



“ Now that I know MND can be inherited, I have chosen to have a genetic test to find out what gene could be responsible for causing my MND. When I get the result I can decide whether to tell my family and then it is up to them if they wish to get tested.”

Choosing to be tested can be a very difficult decision, as it affects the wider family and may raise questions about options relating to pregnancy.

There are currently no preventative measures that can be taken to delay or prevent disease onset (although not every carrier will go on to develop the disease).

We would advise that you seek genetic counselling from a neurological expert experienced in MND. In the first instance talk to your neurological consultant, who will be able to advise.

See *Further information at the end of Part 4: What else might I need to know?* for a list of our research sheets on *Inherited MND*, including detailed information about genetic counselling, genetic testing and options for starting a family.

There has been an acceleration of world-wide research into the disease and its causes, including projects funded by the MND Association. As a result, our understanding of MND and the way motor neurones function is constantly advancing.

Key points

- If tests show that your inherited MND is caused by an identified gene, then unaffected family members can also be tested for the gene defect (if they wish). This 'pre-symptomatic testing' should only be undertaken after genetic counselling due to the psychological and practical implications.

See Further information at the end of Part 4: What else might I need to know? for a list of our research sheets on Inherited MND, which include detailed information about genetic counselling and genetic testing.

- If gene testing reveals that your disease is caused by a mistake in an unidentified gene, then genetic testing will not be available for unaffected family members.
- Some research projects and clinical trials need the participation of people with MND and occasionally their families. We know how keen some people are to help in this way and have developed a research register to help record this interest. Find out more at: www.mndassociation.org/researchlist or contact us to see if you meet the qualifying criteria: Telephone: **01604 611880** Email: research@mndassociation.org

12: Organ and tissue donation



This section looks at the options for organ and tissue donation if you have MND and what to do if you wish to go ahead.

Many people are keen to donate parts of their body after their death to assist others. This can be in the form of organs (parts of the body that perform a specific function, such as the liver), or tissue (groups of cells that work together to make up parts of the body).

It is important to emphasise that donation for transplant and donation for research are not the same:

Donation for transplant: means that organ or tissues are donated to directly help another individual, by transplant into the other person's body.

Donation for research: means that the body, organs or tissue are donated for research or education, often to assist a specific area of research.

The following provides an overview about each type of donation, but if this is something you wish to consider, you should also discuss this with your neurological consultant or specialist palliative care professionals. Each region may have different criteria or procedures that need to be taken into consideration.

See Further information at the end of Part 4: What else might I need to know? for details about our research information sheet on Tissue donation for motor neurone disease research.

Donation for transplant

Only a small proportion of all those who die in the UK each year can donate organs for transplantation.

Although not always possible, people with MND can donate their organs for life-saving transplants. However, the NHS Blood and Transplant authority advises this can only happen if the person dies in certain circumstances in hospital, and the cause is not directly related to MND. For example, following an accident.

In these instances, only organ transplantation is possible, but not use of tissues such as eyes, skin, heart valves and bone. Unfortunately, transplant of tissues is not accepted where MND has been diagnosed.

Organ transplantation can only succeed if organs are removed very quickly after death. This means the person needs to be receiving care in an emergency department, or intensive care unit of a hospital, at the time of their death. As with all organ donations, the transplant clinicians will:

- take into account any medical history
- assess the condition of the donor organ
- use it if it is suitable.

Making arrangements to donate for transplant or for MND research can be complex. If you wish to donate for research and at the same time you are registered as an organ donor (or carry a donor card in case of an accident), it may cause confusion at the time of your death. Ensure that your wishes are made clear to help avoid difficulty for your family at a sensitive time.

You are advised to make your wishes known to your family or those close to you, and to the health and social care professionals involved in your care.

You can change your mind at any point, but again, it is important that you tell everyone involved, including your family, your main health and social care professional contacts and any legal professionals that may have been involved in the original instructions.

If you wish to register as an organ donor, contact the NHS Organ Donor Register:

Telephone: **0300 123 23 23**

Website: **www.organdonation.nhs.uk**

If you live in Wales, The Human Transplantation Wales Act means that people in Wales need to register to say that they do not wish to donate their organs, rather than registering to donate them. Further details can be found by searching for *Human Transplantation Wales Act* at: **www.assemblywales.org**

Donation for research

Although various types of organ and tissue can be donated for research, MND research tends to focus on tissue from the brain and spinal cord.

The brain and spinal cord form the central nervous system of the body and researchers believe that changes found here can help explain the causes of MND and may provide clues about how to combat the disease.

“ I’ve decided to leave my brain to medical science. The consultant mentioned this and I decided to do it...I’ve completed two research projects with him, so I felt comfortable discussing it. My wife was with me at the time.”

People with MND can contribute towards this research by donating their brain and spinal cord tissue after their death. People without MND can also donate their brain and spinal cord tissue for MND research, as this can be used for comparison.

If you wish to donate tissue, try to make arrangements well in advance to ensure that:

- you have time to discuss your wishes with family, those close to you and healthcare professionals
- any necessary consent forms have been completed and signed
- everyone knows the procedure required, so that necessary arrangements happen as quickly as possible after death.

Tissue may not be usable if too much time elapses between your death and its removal. We recommend discussing this with your family to prepare them for the slight risk that it will not be possible to carry out your wishes.

Please note that in England and Wales, tissue can only be taken for research in premises licensed for that purpose.

Tissue banks

Brain and spinal cord tissue donations for MND research are stored and preserved at centres known as tissue banks. In all cases, the samples are coded so the identity of each donor remains strictly confidential. The tissue donation process will be explained to you fully when you contact the tissue bank.

See Further information at the end of Part 4: *What else might I need to know?* for details about our research information sheet on *Tissue donation for motor neurone disease research* which provides further information and a list of the tissue banks with contact details. Or contact our MND Connect helpline, also listed in *Further information*, who can direct you to your nearest tissue bank.

Tissue donation requires removal of the donated brain and spinal cord tissue after your death. The tissue is then prepared for storage. Following this, your body will be transported and retained by your funeral director until your funeral. If you have made arrangements with a tissue bank, you may wish to contact a funeral director in advance to ensure they are aware of what needs to happen after your death.

“ We talked about donating his brain to the tissue bank. The MND nurse became involved and made it easier for us to talk about it... in the end we didn't do this, but it was good to talk about it.”

Key points

- Some tissue banks are not contactable out of hours, so it may be a good idea to ask what would happen if you were to die during a weekend or bank holiday.
- It will not be possible for the tissue bank to provide families with information on how individual samples are used in research, or what was learned from studying them.
- There is usually no charge made for tissue donation, but some tissue banks do not have funding for the donor's body to be transported to them, where the donation occurs. In these cases, the family of the donor are asked to pay for the transport. The cost will vary according to the distance involved and the funeral director transporting the body. Ask the tissue bank and the funeral director for guidance.

13: Suicide and assisted suicide



This section provides an overview about choosing when to die and what is currently legal and illegal (at publication date).

Please be aware that the following contains sensitive information. You only need to read this section if you wish to know more about the legal aspects of suicide and assisted suicide.

We hope this *End of Life* guide will help to reassure you that in most cases of MND, with the right care, dying can be managed to ensure a dignified and peaceful death.

However, some people with MND have told us that they want more information about how to exert choice over the timing of their death and clarity about the legality of these options.

Getting support if you feel distressed

Living with MND can create fear about what may happen as it gets worse. Most people have a more gentle death than they may imagine, but the progression of the disease can feel overwhelming. This may lead to thoughts about control over when you die. However, many people with MND find an unexpected ability to adapt to the challenges ahead and your views can change over time.

If you feel particularly distressed and find the challenges of MND are more than you can cope with, do seek help. Often extreme feelings are due to the wider pressures the disease can create and through fear of becoming a burden to others. With the right support, many problems can be solved or reduced to help you and those close to you achieve a better quality of life. This may help you to feel calmer and consider a range of ways to manage the demands of the disease.

You could talk to:

- a friend, family member or someone you trust
- your GP or a specialist palliative care professional
- our MND Association helpline, MND Connect, on 0808 802 6262
- an adviser through the NHS helpline, NHS 111
- Samaritans 24-hour support service on 116 123, or contact appropriate local helplines
- a religious or spiritual leader.

See Section 16: *Useful organisations, for full contact details.*

See Section 15: *Help from the MND Association, for details about our services.*

See also the following sections:

- 2: *Emotional and psychological support***
- 4: *What to expect as the disease progresses***
- 5: *How will I die?***

Can I choose when to die?

There are a number of ways that you can exert choice and control towards the end of life, without breaking the law. However, this raises questions about suicide and assisted suicide.

In the most basic terms, it is legal to:

- refuse life-sustaining treatments, which you feel are no longer helpful or have become a burden
- take your own life (suicide), where you bring about your own death without any assistance from others.

However, it is **not** legal for someone else to:

- encourage you towards suicide (including advising you how to do this)
- assist you with your suicide.

The following overview explains what is and what is not allowed within the law. It is not intended to replace legal advice or act as guidance to take any specific action.

We recommend discussion with a qualified legal representative should you be concerned about any aspect of control over when you die. You should also talk to specialist palliative care professionals about all available legal options for choice and control at end of life.

What is allowed within the law?

With MND, life will end by allowing the disease to take its natural course, unless another condition, accident or deliberate action causes death first. Doctors can provide you with medication at end of life, to help you relax and reduce distress. Medication cannot be provided to deliberately end your life or hasten death.

See Section 5: *How will I die?*

You can influence how your care will be managed in the later stages using advance care planning. You can also record advance decisions to refuse or withdraw treatment, in the event that you become unable to make or communicate these decisions for yourself.

However, these cannot be used to ask a doctor or any health and social care professional to deliberately cause your death.

See Section 9: *Advance care planning and advance decisions for further details about making advance decisions and what can be included.*

Suicide

To intentionally end your own life is called suicide.

Suicide and attempted suicide are allowed within the law in the UK, as these were decriminalised by the Suicide Act 1961.

However, you cannot ask for help to do this, as it is not legal for someone to actively assist you in any way. To help another person with their suicide is called assisted suicide.

See later heading in this section, *What is not allowed within the law?*

There are many reasons why someone might consider suicide, but the diagnosis of a life-shortening and incurable disease like MND can bring this to the fore. If you are feeling suicidal, do try to talk to someone about your feelings first. Suicidal feelings can be temporary, even if you have found it hard to cope for some time.

See the beginning of this section for suggestions of who you can contact for support.

It may be worth noting down your specific worries and precise reasons why you are thinking about suicide. Also consider the impact of all choices on family, children and friends. When you talk to others, mention these concerns to see if there are alternative ways to solve the issues, so that you can make an informed choice about your next steps.

Make sure you have considered all options, as these may change the way you feel about the way ahead.

What is not allowed within the law?

Assisted suicide in the UK

If someone actively encourages or assists another person with their suicide, it is known as assisted suicide. This is illegal in the UK.

This means you cannot receive practical help or support with your own suicide.

See later heading in this section, *Is it legal to travel to another country for assisted suicide?*

Other people can listen to you talk about your feelings and any intent to kill yourself, but it is against the law for them to take action. For example,

- if someone were to obtain powerful sedatives for you, knowing that you intended to take an overdose to deliberately die, they would be assisting your suicide
- if someone published advice on how to carry out suicide or directed you to any service or organisation that might play a part in helping you to take your own life, they would be assisting your suicide
- if someone tried to persuade you to take your own life, they would be assisting your suicide.

Assisted suicide is illegal under the terms of the Suicide Act 1961 and is punishable by up to 14 years' imprisonment for the person providing the assistance.

Does every case of assisted suicide go to court?

In 2010, the Director of Public Prosecutions at that time, Keir Starmer QC, launched the *Policy for Prosecutors in respect of cases of Encouraging or Assisting Suicide*. This does not change or override the law, but provides a clear framework for prosecutors to decide which cases should proceed to court and which should not.

Prosecution of assisted suicide by the Crown Prosecution Service is considered case by case. Not every instance will necessarily be

brought to court, but this will happen if the prosecutor feels there is a 'public interest'. This means that where factors in favour of prosecution are identified, a court case is to be expected.

For example, this is particularly likely if the act was deliberately publicised to encourage or influence other people to take similar action, or if the person who died:

- did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision about their own suicide
- had not reached a voluntary, clear, settled and informed decision to carry out their own suicide
- was physically able to undertake the act that was provided as assistance.

Prosecution for assisted suicide is less likely if:

- the person who died had reached a voluntary, clear, settled and informed decision to commit suicide
- whoever assisted or encouraged was wholly motivated by compassion
- the actions taken were of minor encouragement or assistance
- whoever assisted had tried to dissuade the person from taking the course of action that resulted in their suicide
- any action was taken reluctantly in the face of the person's determined wish to end their life
- whoever assisted or encouraged, then reported the suicide to the police and fully assisted them with their enquiries into the circumstances.

Any evidence to support these factors must be provided soon after the events. There may be other factors for or against prosecution which could affect the decision. Each case must be considered on its own facts and merits.

For more detail, visit the Crown Prosecution Service website and search for *assisted suicide* at: www.cps.gov.uk

Is it legal to travel to another country for assisted suicide?

Countries outside of the UK may provide options for assisted suicide, but these are only legal in those countries. It is still illegal in the UK to encourage or help someone to travel abroad to make use of these options.

This means that relatives or friends who accompany someone abroad for the express purpose of an assisted suicide, may be subject to legal investigation on their return. All cases of assisted suicide by UK residents, whether carried out in the UK or abroad, are viewed separately.

Again, factors both in favour of and against prosecution will be considered.

Assisted dying

You might hear the term 'assisted dying' being used too. Both assisted dying and assisted suicide refer to someone being assisted to willingly end their own life.

Assisted dying is increasingly used to describe how someone might end their own life in a controlled setting, using medication provided by a doctor. It is sometimes called 'physician assisted dying'.

Whatever term is used and whoever is involved, assisting someone to end their own life is currently illegal in the UK.

Euthanasia

If someone deliberately causes a person's death, in order to relieve them from distress (eg intentional use of medication to end life), it is generally known as euthanasia.

This is illegal in the UK.

This is a complex area, but in simple terms it is regarded as euthanasia even if the person who died:

- asked someone to take this action (because they could not do it themselves)
- was unable to communicate, but had previously stated that they would want their life to end in certain circumstances.

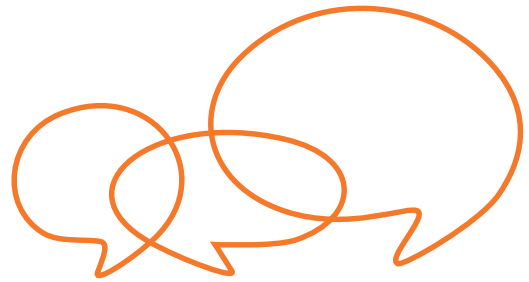
See next page for Summary table of what is allowed and not allowed within the law.

Summary of what is allowed and not allowed within the law

	Allowed	Not allowed
Person with MND	<ul style="list-style-type: none"> • can refuse specific life-sustaining treatments • can record their wishes through an Advance Decision to Refuse Treatment (ADRT) in case they become unable to make these choices in the future • can include a Do not Attempt Cardiopulmonary Resuscitation (DNACPR) order in their ADRT to state that they do not wish for medical teams to attempt resuscitation and in what circumstances <p><i>See Section 9: Advance care planning and advance decisions for more detail about ADRT and DNACPR</i></p> <ul style="list-style-type: none"> • can carry out their own suicide 	<ul style="list-style-type: none"> • cannot expect anyone else to assist them with their own suicide • cannot include a request in an ADRT that will deliberately cause death, eg asking for an injection to end life, or the ADRT will not be legally binding
Relative or friend	<ul style="list-style-type: none"> • can talk to the person with MND about their wishes, needs and preferences at end of life • can assist by ensuring that, if an ADRT is in place, it is accessible for emergency medical teams and other health and social care professionals • can respect the legal wishes and preferences of the person who is approaching end of life 	<ul style="list-style-type: none"> • cannot encourage or assist the person with MND with their suicide • cannot give any advice or information about how to carry out suicide • cannot carry out an act of euthanasia where they deliberately intervene to cause the person's death

	Allowed	Not allowed
<p>Health and social care professional (where qualified to do so)</p>	<ul style="list-style-type: none"> • can talk to the person with MND about their wishes, needs and preferences at end of life • can advise on medical interventions, treatments and withdrawal of life-sustaining treatment • can advise on what to include in an ADRT • can carry out the legal requests made in an ADRT • can administer palliative medicine to ease any pain or anxiety at end of life, particularly when withdrawing life-sustaining treatments 	<ul style="list-style-type: none"> • cannot encourage or assist the person with MND with their suicide • cannot give any advice or information about how to carry out suicide • cannot carry out an act of euthanasia where they deliberately intervene to cause the person's death <p><i>Doctors are also governed by strict regulations, as set by the General Medical Council, which reinforce legal restrictions about how they can proceed if a patient wishes to discuss suicide or assisted suicide.</i></p>
<p>MND Association</p>	<ul style="list-style-type: none"> • can talk to the person with MND about their wishes, needs and preferences at end of life • can provide information resources on symptom management, medical interventions and end of life • can provide a listening ear to help someone talk through their feelings if they are considering suicide • can provide guidance on where to go for support on suicidal feelings, eg health and social care professionals or helplines 	<ul style="list-style-type: none"> • cannot encourage or assist the person with MND with their suicide • cannot give any advice or information about how to carry out suicide • cannot carry out an act of euthanasia where they deliberately intervene to cause the person's death • cannot direct anyone to services or organisations if these are to be used to enable someone to carry out their suicide

14: What people with MND have said about end of life



This section looks at how feedback from people living with or affected by MND, helped to inform the content of this guide.

Although your experience of MND is unique to you, others living with and affected by the disease will share similar fears and concerns about end of life.

Recent studies have revealed that we need to work harder to enable all those affected by MND to:

- consider the available options for symptom management, interventions and potential withdrawal of treatment during the later stages of the disease
- feel more confident about discussing end of life issues with their palliative care specialists and wider health and social care team.

This *End of Life Guide* is one of our responses to these needs, to provide open and candid information about the choices available.

A wide range of resources have been used to provide supporting evidence and qualify the content in this guide, however, the following studies have influenced our approach.

See also *References at the end of this guide for details of how to access further supporting evidence.*

In total, the four projects shown here incorporated over 700 direct contributions from people living with and affected by MND, through a mix of survey and face-to-face interview.

This work indicated that our audience want to feel more informed about end of life decisions.

1: Improving MND Care – motor neurone disease tracking survey 2013 (repeated 2015-16)

In 2013, we published findings from our tracking survey at the MND Association, which had been commissioned through Picker Institute Europe. Our study asked people with MND to give their views on service, support, issues and what is important to them when living with the disease. The survey had previously run in 2005 and 2009, which allows for some comparison to previous results, although certain questions were adapted to meet changes in need and service provision.

951 people responded, which represented about 1 in 3 of those invited to comment. This is the largest survey of its kind for people with MND in the UK to-date, and provides a robust sample to represent their needs and preferences.

We had already commissioned work around the choices people with MND face at the end of their lives.

See next study, 2: *Choices and control when you have a life shortening illness.*

To build on this previous study, questions about end of life concerns were asked in the tracking survey to capture the voice of a larger number of members. 589 people living with MND responded to these additional questions, which provides a significant sample for such a sensitive subject area.

“ I would like to have as much info as possible...it is reality and knowing may take away some of the fear.”

Survey participant, living with MND

2: Choices and control when you have a life shortening illness – researching the views of people with Motor Neurone Disease

We commissioned this study through the Picker Institute Europe to hold an independent investigation into the needs and wishes of people with Motor Neurone Disease (MND) in the area of death, dying and end of life decision-making. Picker interviewed 34 people living with MND and produced the report in 2011/12.

“ They (the MND Association) shouldn’t be frightened of talking about end-of-life issues. Why not be open and talk about it?”

Study participant, living with MND

A wide variety of views were discussed about end of life care and death, but having a voice and self determination were priorities.

“ Some interviewees felt the MND Association had a role in changing attitudes, encouraging people to speak freely and providing information on all aspects of death and dying.”

Executive summary report

A range of recommendations for improving end of life support were made as a result of this work and, at the MND Association, we recognised that we need to:

- work harder to provide opportunities and support for you to talk about end of life issues if you want to do so, including training for our own staff and volunteers
- call for better training and guidance for the health and social care professionals involved in caring for people with MND, so they can have better conversations about end of life issues when appropriate
- lobby for more specialist palliative care to be in place in all parts of England, Wales and Northern Ireland.

The full report can be found on the MND Association website at:
www.mndassociation.org/choices

3: Inquiry into access to Specialist Palliative Care for people with MND

This public inquiry was held by the All Party Parliamentary Group (APPG) for MND, which brought together representatives from all political parties to consider concerns about specialist palliative care for people with MND. The summary report launched in Westminster on 10 March 2011.

Evidence was collected from a wide range of individuals, including people with MND, past carers, neurologists, palliative medicine consultants, hospices and charities. The APPG also heard people’s own experiences and accounts of specialist palliative care.

“ Professionals often say that people with MND and their families do not want to access specialist palliative care shortly after diagnosis – it is too soon. However, once people with MND have accessed specialist palliative care services they say they wished they had accessed services earlier.”

Inquiry summary report

The findings showed that although specialist palliative care is a lifeline for people with MND, and their families and carers, access was variable across the country.

The main recommendations encouraged the development of a national end of life care pathway for people with MND, ring-fenced funding, monitoring and evaluation (to include a review on funding for palliative care), and better planning of specialist palliative care services for people with MND in their locality.

Specific recommendations included the need for improved information provision for MND patients about services and better use of end of life registers, so that providers of palliative care will know about the needs and wishes of patients.

More information about the inquiry and the summary report can be found on our website. Search for All Party Parliamentary Group Inquiry at www.mndassociation.org

The results of the Inquiry continue to be audited to monitor change and further reports will be published to reflect these findings. This aim is to ensure improvement of provision for everyone in need of these services.

4: Difficult conversations – Making it easier to talk about the end of life with people affected by Motor Neurone Disease

Discussions about end of life concerns and decisions are often referred to as ‘difficult conversations’. The NCPC has written a series of *Difficult Conversations* booklets to help health and social care professionals support people with specific conditions. They produced one of these for MND at the end of 2012.

As with the rest of the series, this was written following interviews with people affected by the condition, in this case 60 people living with or affected by MND, and their carers. A wide variety of health and social care professionals, with experience of supporting MND, were also consulted.

This booklet aims to help relevant professionals become more confident about what to expect when discussing end of life with people affected by MND. It is hoped the booklet will encourage open conversations about end of life wishes, preferences and fears.

“ Be honest and say it how it is, but say it as gently as possible.”

Study participant, living with MND

The subjects covered include:

- Why talk about it at all?
- What can happen if you avoid the subject?
- Topics of conversation
- When to talk
- How to start conversations

The booklet can be purchased through the NCPC website at:
www.ncpc.org.uk/difficult_conversations

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 4: *What else might I need to know?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 9A to 9C: our range of sheets on thinking and emotions in MND
- 14A: Advance Decision to Refuse Treatment (ADRT)

From our research information sheet range:

Research sheet B:

- Part one – Introduction to inherited motor neurone disease
- Part two – Genetic testing and insurance
- Part three – The options available when starting a family

- C: Unproven treatments
- D: Clinical trials: what are they and how are they organised?
- F: Stem cells and MND
- G: Statins and MND
- I: Tissue donation for motor neurone disease research

From our other publications:

What I should expect from my care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Caring and MND support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

Caring and MND quick guide a small A5 booklet to help someone new to the caring role become aware of available support.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:

Telephone: 0808 802 6262

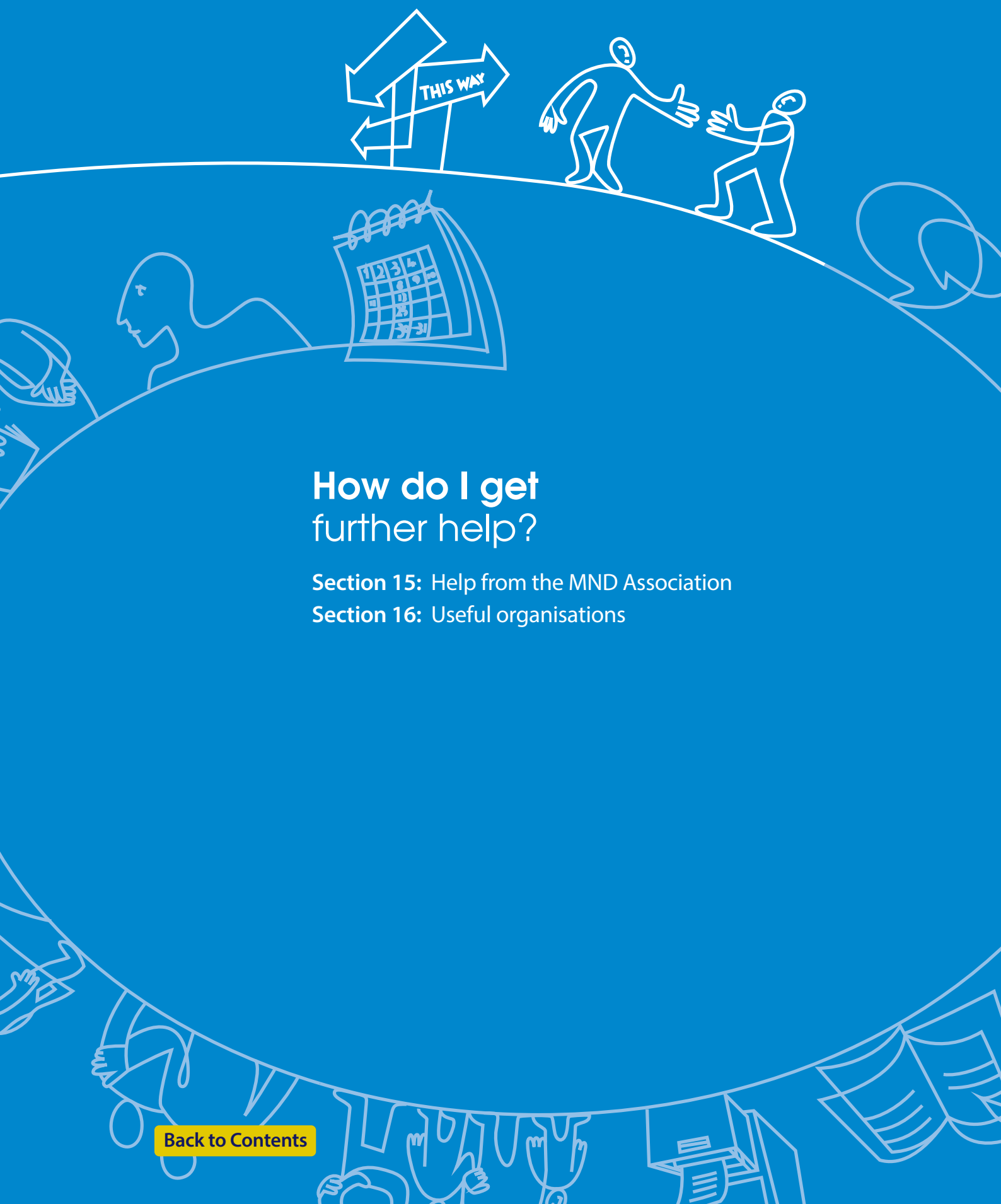
Email: mndconnect@mndassociation.org

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

See Section 15: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at: <http://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.



How do I get further help?

Section 15: Help from the MND Association

Section 16: Useful organisations

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15: Help from the MND Association

This section will help you access services and support from the MND Association.

At times, you may feel very isolated, but you are not alone.

“ The MND Association is there at the end of a phone or email... and with them I’m a member of a community with similar problems; we can provide each other with help and offer solutions. This has given me a sense of purpose.”

We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. The following explains how you can access our support, as and when needed, including guidance about information and services relating to end of life.

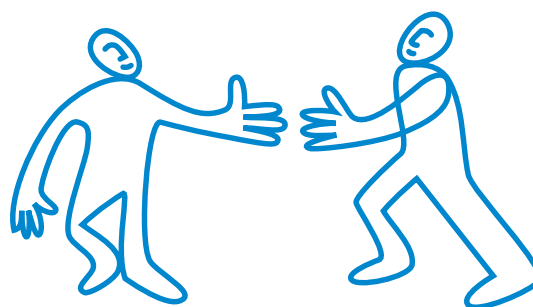
Our ultimate vision is a world free from MND.

Our mission is to:

- improve care and support for people with MND, their families and carers
- fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND
- campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

MND Connect helpline

The MND Connect helpline is our support and information service for people living with MND, their families, carers, our volunteers and health and social care professionals.



“ I was in contact with you and your advisers during a very difficult time, and was always given help and time to talk, something I found really invaluable... We were able to gain knowledge about the condition, and were prepared (as much as you can be) for each stage of the illness and the options available.”

If you are concerned about end of life, or any aspect of MND, the team will be happy to listen and advise in any way they can. They will also be able to help direct you to appropriate external services for further support or guidance.

The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Association

PO Box 246, Northampton NN1 2PR

Health and social care professionals can also contact the helpline for guidance and information about MND.

MND Connect is accredited by the Helplines Standard.



Association visitors (AVs)

AVs are volunteers who provide free and confidential personal support to people living with MND, their carers, their family and close friends. An AV can help you identify problems as they arise and discuss your choices for how these might be managed. AVs can make contact with you by phone, email or home visit.

“ My Association visitor has been really, really helpful. She’s been prepared to help and support whenever I’ve asked and has been very good at keeping one eye on the future.”

All AVs are carefully selected, undergo a thorough training programme and a Disclosure and Barring Service (DBS) check. This was formerly known as a Criminal Records Bureau (CRB) check.

If you would like to be supported by an AV, please contact your local regional care development adviser (RCDA). If an AV is not available in your area, we can offer ongoing support and help through regular contact with the MND Connect helpline, or your local branch or group. Please see other listed services in this section for details.

Our work with volunteers is accredited by the Investing in Volunteers standard.



Regional care development advisers (RCDAs)

Our regional care development advisers either have a professional health or social

care background or they have significant experience that will support them in the role. They have expert knowledge of the management and care of people with MND and work closely with local service providers to ensure care and support is available at the right time.

A key part of their role is to influence statutory services and to advise in complex situations, including how end of life care is managed. They also manage our regional teams of Association visitors (AVs).

“ The regional care development adviser has been excellent in helping when equipment I needed has taken months to arrive. Also when there was a problem with no support for my wife as my carer managing this disease.”

Our regional care development advisers are listed on our website, or you can contact our helpline (see previous MND Connect helpline heading).

Local branches and support groups

We have a network of around 90 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide a warm welcome, friendship and the opportunity to meet others affected by MND.

“ Friendships have been formed with like-minded individuals who all have differing levels of MND and are at different stages of the disease... the camaraderie between survivors and carers is so important to us all in our support group. We are there for each other through thick and thin.”

Our branches and groups offer guidance and support, including newsletters and regular meetings, including get togethers and group meetings specifically for carers. Our branches are listed on our website with contact details, or contact MND Connect to help you find the nearest location (see previous *MND Connect Helpline* heading).

MND Care Centres / Networks

MND Care Centres and Networks can offer the specialist help you may need, to cope with the complexity of the disease.

All of the centres and networks use specialist doctors and nurses to coordinate the care of people with MND.

The MND Association has established and part-funds more than 20 MND Care Centres and Networks across the UK. The Care Centres are based in large hospitals and the three networks operate with outreach teams.

If you cannot access one of these centres or networks easily, you can still receive coordinated support through regional neurological services and local specialist palliative care services.

“ The Care Centre staff are all brilliant. It’s a great place to go to solve medical problems and it’s good meeting other people with MND as well.”

MND Care Centres:

- are based in Regional Neuroscience Centres with a dedicated MND clinic and a dedicated single point of contact for people with MND
- enable access to a multi-disciplinary team with expertise in the management of MND
- have strong links with the MND Association and local community services
- spread expertise through education and by sharing good practice with colleagues in the community

- are the location for clinical drug trials and undertake clinical research.

The networks work in a similar way, but do not have a fixed location, in order to provide a service across a wide geographical area.

You may need to ask your GP for a referral to access MND Care Centres and Networks.

The MND Care Centres and Networks are also listed on our website with contact details, or contact MND Connect to find out about the nearest location (see previous *MND Connect Helpline* heading).

“ I receive excellent care at the MND Care Centre. Help is just a phone call away, plus there are once-a-month support meetings run by the hospital and separate monthly support meetings by the MND Association branch.”

Equipment loan and MND support grants

Following a diagnosis of MND, our Support Services team may be able to provide certain items of equipment and communication aids on loan, or consider financial support requests for a variety of needs, such as respite care, home adaptations or equipment rental. We provide support grants for people with MND and carers, and children or young people close to someone with MND.

“ I’ve had excellent advice about preparing well in advance for the ‘disasters and indignities’ ahead, I’ve had financial support to alleviate the costs of the move downstairs... I’ve also been provided with a recliner seat.”

All statutory funding and services should be explored first, but loaned items can be provided while you wait for services to arrange equipment or where an item cannot be supplied this way. In most cases, initial requests must be made to us by a health and social care professional, following assessment of your needs. If you have any queries, contact:

Telephone: **0808 802 6262**
Email: mndconnect@mndassociation.org
MND Association
PO Box 246, Northampton NN1 2PR

Benefits Advice Service

The MND Association Benefits Advice Service provides free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: **0808 801 0620** (England & Wales)
0808 802 0020 (Northern Ireland)
Email: Through the website contact page, at:
www.mndassociation.org/benefitsadvice

Wheelchair Support Service

If you need information on wheelchairs, experience delays in assessment or provision, or require top-up features, our wheelchair service may be able to help.

Telephone: **0808 802 6262**
Email: wheelchairs@mndassociation.org

“ My wheelchair has really changed my life, I can't thank you enough.”

Communication Aids Service

Help with queries about communication aids, for people with or affected by MND, and health and social care professionals. A limited amount of financial support can be provided, and some items on loan (if unavailable or delayed through health and social care services).

Telephone: **0808 802 6262**
Email:
communicationaids@mndassociation.org

Care information and publications

We provide a wide range of information, developed and revised under The Information Standard, an accreditation run by NHS England. This means they are considered trustworthy. Look for the following marker:



“ I have been asked to contribute to some of the resources. It's so refreshing to see a version that has been significantly amended, on account of feedback which has clearly been absorbed. All too often, organisations consult but don't listen... this is a great example of an organisation that consults effectively.”

You can download the majority of our care information from our website, including our publications list, using the following address: www.mndassociation.org/publications or contact MND Connect to order printed copies (see previous *MND Connect helpline* heading).

Our website

The MND Association makes every effort to ensure it provides trustworthy information (see previous *Care information and publications* heading). Please visit the MND Association website to find out more about MND, our services and the Association at: www.mndassociation.org including news about our research, volunteering, fundraising and campaigning activities.

“ The website and downloads have been extremely good – well-targeted and accurate, providing a wealth of very useful information.”

Our online forum

A safe place to share experiences and tips with others affected by MND.

“ The forum is so useful for all of us as carers and sufferers, it's a lifeline... I still can't leave it, even though I no longer need it.”

Access the forum on our website, or at: <http://forum.mndassociation.org>

Membership

Membership of the MND Association is free for people living with MND, their spouses, partners and carers. It enables you to join a community of people who share the same vision of a world free of MND. This creates a powerful voice to support campaigns on behalf of all those affected, demonstrating that we represent a significant number of people living with or affected by the disease.

“ As a member, I find all the communication has been most helpful and I feel supported.”

As a valued member you will enjoy a number of unique benefits:

- a welcome pack, including a personal membership card.
- our quarterly membership magazine, *Thumb Print*
- an optional link to your nearest branch or group

- attendance and voting at our annual meeting (AGM)
- invitations to our exclusive conferences and events.

“ At the AGM last September we met people from all over the country. There were also people from the MND Association and a doctor from Sheffield talking about the latest research.”

To find out more, see:

www.mndassociation.org/membership.

To become a member, you can contact us on 01604 611855, or if preferred by email: membership@mndassociation.org

Support for minority and ethnic groups

We are here for everyone living with or affected by MND.

We are aware that not everyone will have the same needs, as everyone's experience of MND will be unique. Culture and religion may also influence the way care and support should be provided and the MND Association supports diversity and equality in all of its services.

Please ask the service you are dealing with if you have any particular preferences or needs that you wish to be taken into consideration.

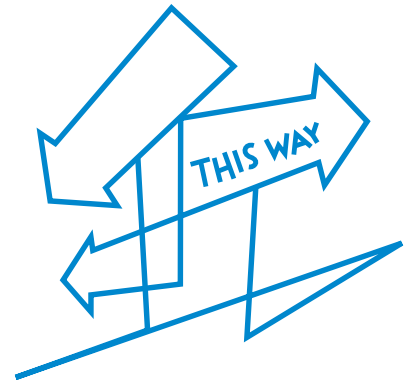
Key points

- Our MND Connect helpline is not just here to provide information, the team can also offer a listening ear if you just need to talk. MND Connect supports people living with MND, their families, carers and health and social care professionals.
- Before contacting us about equipment loan or financial support, try to gain an independent assessment of your needs by an appropriate health and social care professional.

See [Section 16: Useful organisations for further contacts](#).

16: Useful organisations

This section will help you identify some of the organisations that are likely to become frequent sources of information or service.



You can access a wider list of useful organisations on our website at: www.mndassociation.org/usefulorgs. We also list relevant organisations at the end of all our information sheets.

You may also wish to contact your local branch or group, an Association visitor or our helpline MND Connect, to ask about external services and advice about local support.

[See Further information at the end of this section for contact details.](#)

Your local authority or council will also have lists of regional providers and may offer a directory of services on their website.

Organisations

Please note, we do not necessarily endorse the organisations listed here and cannot be held responsible for anything stated on their website or supplied as a service or product.

We keep this information updated, but the contact details may be subject to change before the next revision. If you need help locating an organisation, please contact our helpline MND Connect.

[See Section 15: Help from the MND Association for all our service contact details.](#)

Age UK

Advice and information for people in later life, including support on benefits.

Age UK, Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: **0800 678 1174** (England)

08000 223 444 (Wales)

0808 808 7575 (Northern Ireland)

Email: through the website contact page

Website: www.ageuk.org.uk

arrangingafuneral.co.uk

Guidance and support about arranging a funeral.

arrangingafuneral.co.uk, 142 Cromwell Road, Kensington, London SW7 4ET

Telephone: **0800 0198 451**

Email: through the website contact page

Website: www.arrangingafuneral.co.uk

BACP (British Association for Counselling and Psychotherapy)

Advice on how to seek counselling and psychotherapy support, with directions to trained practitioners.

BACP, BACP House, 15 St John's Business Park, Lutterworth LE17 4HB

Telephone: **01455 883300**

Email: bacp@bacp.co.uk

Website: www.bacp.co.uk

Bereavement Advice Centre

This organisation has produced an A5 booklet called *What to do when someone dies, A practical guide*, which helps advise on the legal and practical steps to take after someone's death.

Bereavement Advice Centre, Simplify,
Heron House, Timothy's Bridge Road,
Stratford Upon Avon CV37 9BX
Telephone: **0800 634 9494**
Website: www.bereavementadvice.org

Carers Trust

Information and support for all those who find themselves in a caring role.

Carers Trust, 32-36 Loman Street,
London SE1 0EH
Telephone: **0300 772 9600** (England)
0292 009 0087 (Wales)
Email: info@carers.org
Website: www.carers.org

Carers UK

Information and support for all those who find themselves in a caring role.

Carers UK, 20 Great Dover Street,
London SE1 4LX
Telephone: **0808 808 7777**
(England and Wales)
028 9043 9843 (Northern Ireland)
Email: through the website contact page
Website: www.carersuk.org

Childhood Bereavement Network

Information and support for bereaved children, with directions to other national and local services.

Childhood Bereavement Network, 8 Wakley
Street, London EC1V 7QE
Telephone: **020 7843 6309**
Email: cbn@ncb.org.uk
Website: www.childhoodbereavementnetwork.org.uk

Childline

A counselling service for children and young people, with a free 24 hour helpline for children in distress or danger.

Childline, Via NSPCC, Weston House, 42
Curtain Road, London EC2A 3NH
Telephone: **0800 1111**
Email: through website and confidential login
Website: www.childline.org.uk

The Cinnamon Trust

An organisation dedicated to helping people in later years, or with life-shortening conditions, to find foster care or alternative homes for their pets.

The Cinnamon Trust, 10 Market Square,
Hayle, Cornwall TR27 4HE
Telephone: **01736 757 900**
Email: through website contact page
Website: www.cinnamon.org.uk

Citizens Advice

Free guidance to resolve legal, money and other problems. Search for your local branch on the Get Advice page of the website.

Telephone: **03444 111 444** (England)
03444 77 20 20 (Wales)
028 9023 1120 (Northern Ireland)
Website: www.citizensadvice.org.uk

Community Law Service

Independent advice and representation, including help on welfare benefits, debt and housing. Find your local service through your telephone directory or online.

Conversations for Life

Help for families, professionals and communities to start discussions about end of life care.

Conversations for Life, 2 The Mill Yard, Staveley, Cumbria LA8 9LR
Telephone: **01539 234108**
Email: info@conversationsforlife.co.uk
Website: www.conversationsforlife.co.uk

Cruse Bereavement Care

Cruse is a leading bereavement charity in the UK, offering information, advice and support.

Cruse Bereavement Care, PO Box 800, Richmond, Surrey, TW9 1RG
Helpline: **0808 808 1677**
Website: www.cruse.org.uk

Disability Law Service

Assistance on disability law.

Disability Law Service, The Foundry, 17 Oval Way, London SE11 5RR
Telephone: **0207 791 9800**
Email: advice@dls.org.uk
Website: <http://dls.org.uk>

The Disabled Living Foundation

A wide range of support and advice for people with disabilities, including information on daily living equipment.

The Disabled Living Foundation, Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE
Telephone: **0300 999 0004**
Email: info@dlf.org.uk
Website: www.dlf.org.uk

Dying Matters

A membership organisation offering a wide range of resources to help people start conversations more easily about dying, death and bereavement. See also *Find Me Help*.

Dying Matters, c/o The National Council of Palliative Care, 34-44 Britannia Street, London WC1X 9JG
Telephone: **020 7697 1520**
Email: through the website contact page
Website: www.dyingmatters.org

Find Me Help

Online service with a search facility to help you find local services that can assist with end of life needs. This is hosted on the Dying Matters website.

Website: <http://help.dyingmatters.org>

Funeral Planning Authority (FPA)

The FPA is an independent regulatory organisation working to protect consumer rights within the funeral planning sector.

Funeral Planning Authority, Barham Court, Teston, Maidstone, Kent ME18 5BZ
Telephone: **0845 601 9619**
Email: info@funeralplanningauthority.co.uk
Website: www.funeralplanningauthority.co.uk

GOV.UK

Online government advice, including information on benefits and related entitlements. You can access associated claim forms through the website.

Email: all email addresses can be found on the website, related to the type of enquiry
Website: www.gov.uk
www.nidirect.gov.uk (Northern Ireland)

Health and Care Professions Council (HCPC)

A regulatory body with a register of health professionals who meet their standards of practice, including psychologists, physiotherapists, occupational therapists and speech and language therapists. You can use their Check the Register facility to see if a relevant professional has been registered.

Health Professions Council, Park House 184 Kennington Park Road, London SE11 4BU
Telephone: **0300 500 6184**
Website: www.hcpc-uk.co.uk

Healthtalk.org

A website database of personal and patient experiences, including a series of interviews with people affected by or living with MND.

Email: info@healthtalk.org
Website: www.healthtalk.org (search for *motor neurone disease*)

Hospice UK

An organisation offering information about hospice care, what services are available, who provides them, who can receive hospice care and how to get referred.

Hospice UK, 34-44 Britannia Street, London WC1X 9JG
Telephone: **020 7520 8200**
Email: info@hospiceuk.org
Website: www.hospiceuk.org

Humanists UK

An organisation that can provide guidance and support for funerals where no religious content is wanted.

British Humanist Association, 39 Moreland Street, London EC1V 8BB
Telephone: **020 7324 3060**
Email: ceremonies@humanism.org.uk
Website: <https://humanism.org.uk>

Institute of Civil Funerals

An organisation that can advise on civil funerals, with a search facility to locate civil celebrants.

Institute of Civil Funerals, 186a Station Road, Burton Latimer, Kettering, Northamptonshire NN15 5NT
Telephone: **01480 861411**
Email: info@iocf.org.uk
Website: www.iocf.org.uk

Marie Curie

Marie Curie is a UK charity dedicated to the care of people with terminal illnesses, including non-cancer patients.

Marie Curie, 89 Albert Embankment, London SE1 7TP
Telephone: **0800 090 2309**
Email: online chat available through website
Website: www.mariecurie.org.uk

Macmillan Cancer Support

Macmillan focuses mainly on people affected by cancer but they do provide some support for non-cancer patients. Ask your health and social care team for advice about Macmillan nurses and services in your area.

Macmillan Cancer Support, 89 Albert Embankment, London, SE1 7UQ
Telephone: **0808 808 00 00**
Email: through the website contact page
Website: www.macmillan.org.uk

Medic Alert

A registered charity providing an identification system for individuals with medical conditions and allergies, usually in the form of bracelets or necklets, and supported by a 24 hour emergency telephone service.

MedicAlert, MedicAlert House,
327 Upper Fourth Street,
Milton Keynes MK9 1EH
Telephone: **01908 951045**
Email: info@medicalert.org.uk
Website: www.medicalert.org.uk

Motability

For details about vehicle leasing or hire purchase through the Motability scheme.

Telephone: **0300 456 4566**
Email: through the website contact page
Website: www.motability.co.uk

MND Scotland

Formerly the Scottish Motor Neurone Disease Association, providing care, information and research funding for people affected by MND in Scotland.

MND Scotland, 2nd Floor, City View,
Eagle Street, Glasgow G4 9XA
Telephone: **0141 332 3903**
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

National Association of Funeral Directors (NAFD)

Advice on funeral arrangements and location of registered funeral directors. Members must comply with its Code of Practice.

National Association of Funeral Directors,
618 Warwick Road, Solihull,
West Midlands B91 1AA
Telephone: **0121 711 1343**
Email: info@nafd.org.uk or use contact page
Website: <http://nafd.org.uk>

The National Society of Allied and Independent Funeral Directors (SAIF)

An organisation providing advice on funeral arrangements and location of registered funeral directors. The National Society of Allied and Independent Funeral Directors has a code of practice for its members.

The National Society of Allied and Independent Funeral Directors, 3 Bullfields,
Sawbridgeworth, Hertfordshire CM21 9DB
Telephone: **0345 230 6777**
Email: info@saif.org.uk or use contact page
Website: <http://saif.org.uk>

The National Council for Palliative Care

A charity supporting all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. They work with government, health and social care staff, and people affected by end of life issues to improve end of life care for all.

The National Council for Palliative Care,
34-44 Britannia Street, London WC1X 9JG
Telephone: **020 7697 1520**
Email: through the website contact page
Website: www.ncpc.org.uk

Natural Death Centre

A source of information and advice if you are thinking about arranging a funeral without a funeral director and using a natural burial ground.

Natural Death Centre, In the Hill House,
Watley Lane, Twyford, Winchester SO21 1QX
Telephone: **01962 712 690**
Email: rosie@naturaldeath.org.uk
Website: www.naturaldeath.org.uk

NHS Choices

Online information to help you make informed choices about health. NHS Choices also hosts an Information Prescription Service, for trustworthy healthcare information according to need or condition.

Telephone: see NHS 111 for helpline
Email: through the website contact page
Website: www.nhs.uk

NHS 111 (previously known as NHS Direct)

The NHS online/telephone help and support for urgent (but not emergency) health advice and information, 24-hours a day, 365 days a year.

Telephone: **111**
Email: through the website contact page
Website: search for NHS 111 at: www.nhs.uk

NHS Direct Wales

Similar to NHS 111, but for medical advice in Wales.

Telephone: **0845 46 47**
Website: www.nhsdirect.wales.nhs.uk

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service.

Email: through the website contact page
Website: <http://online.hscni.net>

NI Direct

The equivalent of GOV.UK for Northern Ireland, providing government information, eg guidance on benefits. This is an online service.

Email: through the website contact page
Website: www.nidirect.gov.uk

The Office of Care and Protection

The organisation that handles applications for Enduring Power of Attorney (EPA) in Northern Ireland.

Office of Care and Protection, Room 2.2A, Second Floor, Royal Courts of Justice, Chichester Street, Belfast BT1 3JF
Telephone: **028 9072 4733**
Website: search for *enduring power of attorney* at: www.nidirect.gov.uk

Office of the Public Guardian

The organisation that handles applications for Lasting Power of Attorney (LPA) in England and Wales.

Office of the Public Guardian, PO Box 16185, Birmingham B2 2WH
Telephone: **0300 456 0300**
Email: customerservices@publicguardian.gsi.gov.uk
Website: search for *office of the public guardian* at: www.gov.uk

Record Me Now

A downloadable free app to leave video messages for family and children, so you can provide love and guidance after death.

Email: director@recordmenow.org
Website: www.recordmenow.org

Samaritans

Confidential non-judgemental emotional support, 24 hours a day, for people experiencing feelings of distress or despair. Their service is available by telephone, email, letter or face-to-face in most of their branches. Contact your local branch or:

Samaritans, Freepost RSRB-KKBY-CYJK, PO Box 9090, Stirling FK8 2SA
Telephone: **116 123**
Email: jo@samaritans.org
Website: www.samaritans.org

Sue Ryder Care

A charity providing a range of services for people who are terminally ill, in their own homes, day centres, Sue Ryder hospices and care centres. They also provide neurological centres for people with long term neurological conditions.

Sue Ryder, First Floor, 16 Upper Woburn Place, London WC1H 0AF
Telephone: **0845 050 1953**
Email: **info@sueryder.org**
Website: **www.sueryder.org**

Tell Us Once

A service through GOV.UK that enables someone to inform government departments that a person has died in order to stop benefits and related support, without having to make repeated contact. The service is available in England, Wales and Scotland. It does not apply to Northern Ireland. Access the service through your local register office or online:

Website: **www.gov.uk/tell-us-once**

Winston's Wish

A bereavement charity to help children after the death of someone close. The website has a section for parents and an interactive area for children and young people.

Winston's Wish Head Office,
17 Royal Crescent, Cheltenham GL50 3DA
Telephone: **08088 020 021** (helpline)
Email: **info@winstonswish.org.uk**
Website: **www.winstonswish.org.uk**

Key points

- Always try to obtain an independent assessment of your needs before approaching commercial companies for products or services. For example, see an occupational therapist before purchasing any costly equipment or aids. You need to be aware of what will be suitable for you and whether your needs are likely to change.

Further information:

We produce a wide range of publications to help you gather information about MND and its management. Our resources include a numbered range of information sheets and larger guides.

How to access publications and further information:

Most of our publications can be downloaded from our website:

www.mndassociation.org/publications or you can order them from the **MND Connect Helpline:**

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

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

See Section 17: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at:

<http://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

Acknowledgements

Our thanks to the following:

For sharing their experiences and views:

All those living with MND and their families who have contributed to our surveys, studies or provided feedback. It is only through your willingness to share personal experience that we have been able to explore end of life with MND with such candour. Thank you for inspiring the development of this guide.

Our review group of people living with MND, carers and ex-carers for their commitment in helping us to continually improve the content of our information. Your ongoing support and hard work is hugely valuable and makes a difference.

The Mepham family for kindly sharing their detailed report *The Mepham Family's Experience of Motor Neurone Disease 2009-2010*, written in recognition of Roy Mepham, to help improve end of life care for others with MND.

For their expert guidance, reviews or support:

Debi Adams, Clinical Nurse Specialist in Palliative Neurology, St Catherine's Hospice, Scarborough

Jo Black, Community Involvement Manager, The National Council for Palliative Care

Idris Baker, Consultant in Palliative Medicine, ABM University Health Board, South Wales

Colin Campbell, retired Palliative Medicine Consultant, Saint Catherine's Hospice, Scarborough

Simon Chapman, formerly Director of Policy & External Affairs at NCPC & Dying Matters, now consulting via @SimonSimply

Annette Edwards, Consultant in Palliative Medicine, Leeds Teaching Hospitals NHS Trust/ Sue Ryder Wheatfields Hospice, Leeds. Chair of Association for Palliative Medicine's Special Interest Forum on neurological palliative care.

Christina Faull, Palliative Medicine Consultant, LOROS, Leicester

Lesley Johnston, Advice and Information Officer, Carers Northern Ireland

Amanda Mobley, Clinical Psychologist, Community Neuro-Rehabilitation/Stroke, Walsall Healthcare NHS Trust

Dame Barbara Monroe, Chief Executive, St Christopher's Hospice, London

David Oliver, retired Consultant in Palliative Medicine, formerly at the Wisdom Hospice, Rochester and Honorary Professor, Tizard Centre, University of Kent, Canterbury

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References

An extensive reference list of the evidence used to support this guide is available on request. Please make your request by email to: infofeedback@mndassociation.org or write to us at:

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