



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

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

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

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org



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

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.

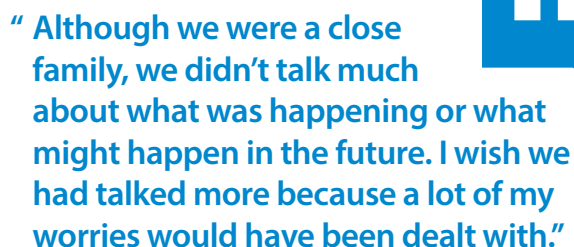
Talking about dying with children and young people

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.

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For references and acknowledgements please
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