



3: Difficult conversations with professionals

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

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

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.

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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