

## 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.**

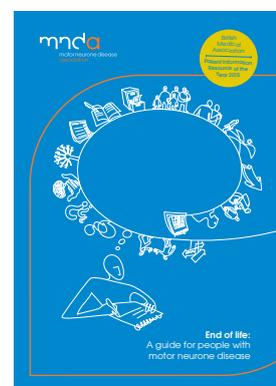
The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

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

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

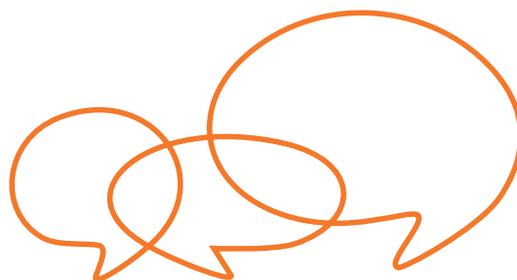
Telephone: 0808 802 6262

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



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

# 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.

Previous studies revealed that we needed 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.

One of our responses was to develop this guide, to inform you about the choices available. We continue to revise and update this resource. Originally launched in 2014, the following four studies helped inspire our content.

**See also *References* at the end of this guide for details of how to access further supporting evidence.**

These studies include contributions from more than 700 people living with or affected by MND, gathered through survey and face-to-face interviews. This work revealed that our audience want to feel more informed about end of life decisions.

## **1: Improving MND Care – motor neurone disease tracking survey**

We run this survey on a regular basis to ask people with MND for their views on service, support and what is important to them when living with the disease.

In 2013 we asked the Picker Institute Europe to run this survey and 951 people responded. This represented about 1 in 3 of those invited to comment. This was the largest UK survey for people with MND at that time. The results provided a robust sample of their needs and preferences.

Following previous investigations, we decided to include an optional section in this survey, with questions about end of life concerns. 589 people living with MND responded. This was a significant number for such a sensitive subject area.

Questions about end of life needs have been repeated in subsequent tracking surveys to help us understand and respond.

**“ 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 early study through the Picker Institute Europe to hold an independent investigation into the needs and wishes of people with 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.

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 discuss 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.

**“ 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

## 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.

Results from this inquiry still influence our efforts to improve end of life discussions and care, for people with or affected by MND. Find out more on our recent work by searching for *All-Party Parliamentary Group* at [www.mndassociation.org](http://www.mndassociation.org)

#### **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'.

In 2012, the National Council for Palliative Care (NCPC) added to their series on Difficult Conversations, with this booklet about MND. The aim was to help health and social care professionals open discussions with better understanding of the condition. As an organisation, the NCPC has since joined with Hospice UK, but this was an important publication to support professionals.

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.

The aim of this booklet was to give relevant professionals a better idea of what to expect when discussing end of life with people affected by MND.



**“ Be honest and say it how it is, but say it as gently as possible.”**

Study participant, living with MND

The subjects covered influenced development of this guide, including:

- Why talk about it at all?
- What can happen if you avoid the subject?
- Topics of conversation
- When to talk
- How to start 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
- 14A: Advance Decision to Refuse Treatment (ADRT)

### From our research information sheet range:

Research sheet B:

Part one – Introduction to inherited MND

Part two – Genetic testing and insurance

Part three – Options when starting a family

- C: Unproven treatments
- D: Clinical trials
- F: Stem cells and MND
- G: Statins
- I: Tissue donation

### From our other publications:

***What you should expect from your 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

***Telling people about MND*** ways to open difficult conversations with family, children, friends and professionals.

***Emotional and psychological support*** for suggestions and details about therapies.

### How to access publications and further information:

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

Telephone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto: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 staff.

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

### Online forum:

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

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For references and acknowledgements please  
refer to the full guide, *End of life: A guide for  
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This resource has been evidenced,  
user tested and reviewed by experts.