



## 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.

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](http://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](http://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](http://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](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 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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MND Association  
PO Box 246, Northampton NN1 2PR  
Tel: 01604 250505  
Website: [www.mndassociation.org](http://www.mndassociation.org)

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For references and acknowledgements please  
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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](http://www.england.nhs.uk/tis)