mnda
motor neurone disease
association

Response to The National Council for Palliative Care (NCPC) review of choice in end of life care

Introduction

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

End of life care occupies a central position in the Association's work. In the last two years, we have undertaken a groundbreaking qualitative study of the attitudes of people living with MND to end of life and dying, conducted the largest ever survey of people with MND in the UK on these issues and published the first comprehensive information guide on end of life issues for people with MND. These documents are attached as appendices and form the basis of our response.

We welcome the Government's decision to task NCPC with conducting a review of choices in end of life care, and we are pleased to have the opportunity to input into the review on behalf of people with MND and their families.

What people with MND tell us

We can draw on two significant pieces of research when outlining what people with MND think about choice at the end of life.

In 2012 we published *Choice and control when you have a life-shortening illness*, a report by the Picker Institute Europe, commissioned by us, which examined the views of 34 people living with MND on end of life issues.

Then, in 2013 we conducted the largest ever survey of people with MND in the UK on a range of issues, including end of life care. The *Improving MND Care* survey collected the experiences and views of more than 950 responses from people living with the disease in England, Wales and Northern Ireland. Three-fifths of respondents (62%) (n=589) to the survey opted to complete some or all of the questions about end of life.

The full reports are attached as appendices; what follows is a summary of the key findings relating to choice, for the review.

Having control

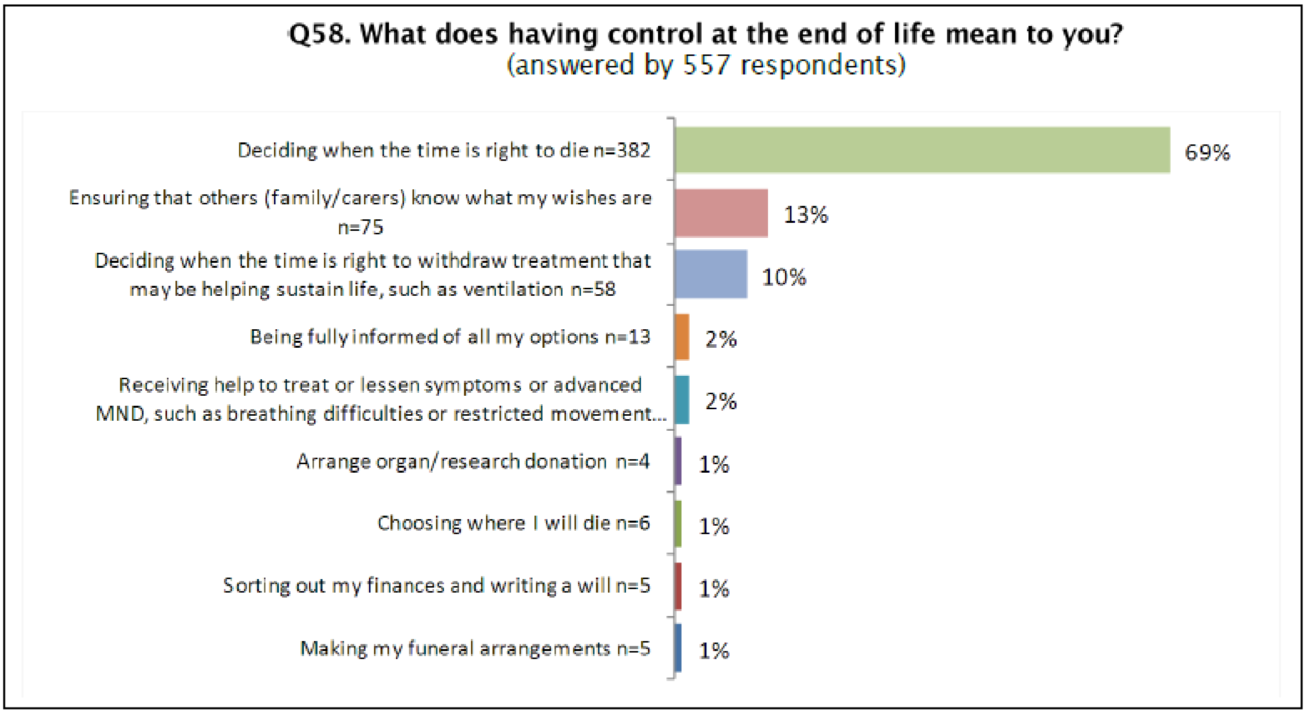
Maintaining control is incredibly important to people with MND. As a rapidly progressing condition, MND takes away a lot of control from the person: the ability to speak, to walk, to use one's arms, to hold one's head up – and more.

Most of the people interviewed in the 2012 research said it was important to them to have choices at the end of their life, but the researchers found that choice and control meant different things to different people:

> *"Some interviewees said they had taken control by making detailed plans specifying their preferences for care and treatment, stating what interventions were acceptable or not and what they would prefer to happen at the end of their life. Some felt reassured by the knowledge that doctors and family members were aware of their wishes; others were less confident that their wishes would be carried out."*

Our 2013 survey provided the opportunity to directly ask people with MND what having control at the end of life means to them.

Two thirds said that having control at the end of life meant 'deciding when the time is right to die'. The second most popular response was 'ensuring that others (family/ carers) know what my wishes are' and 'Deciding when the time is right to withdraw treatment that may be helping to sustain life' was the third most selected option.



These findings echoed those of the 2012 study. Researchers noted that for some interviewees, having control meant being able to decide *when* and *how* they died. Some said that not having this control was causing them additional distress:

> *"I'd like to be in control. I'd like to decide when I've had enough. I think I will want to take the decision to end my life while I can. I don't want to go beyond that where somebody else has to do it."*
> *[male, face-to-face interview)*

> *"My only concern is having the ability to conclude my life when I think it is appropriate."*
> *(male, telephone interview)*

> *"Humans have evolved with intelligence, choice, independence and dignity, so I think people with terminal illnesses should be allowed to make plans for a suitable time to end their life."*
> *(female, email interview)*

Some people hold strong views on this issue before their diagnosis of MND, others develop these views as a result of having the disease. Views on assisted dying is discussed more in detail in the full report (Appendix 2) and the topic is addressed in our information guide (Appendix 3).

It is important to note that wishes and perceptions of control often change as MND progresses. The 2012 researchers discuss this:

> *"Several interviewees said that their attitudes towards death and dying had changed with time, as their MND progressed. Some said that their earlier views had softened as they found they were able to deal with more than they thought possible, and some considered their quality of life to be good. As a result, a few interviewees wanted to rescind earlier advance directives to refuse treatment*
>
> *[...]*
>
> *Having information about all their possible options and having the ability to choose between them, was important to many interviewees. End-of-life decisions were seen as highly personal and subject to change as MND progressed. There was general agreement that the MND Association should be promoting informed choice and self-determination throughout the illness and at the end-of-life."*

Talking about dying

The 2012 researchers reported that:

> *"Many interviewees said they found talking about end of life care issues very difficult; several said despite a natural reluctance, they needed to talk. Some interviewees said that talking about difficult issues with doctors, hospice staff and with families and friends helped clarify their thinking, as well as giving them support. Some had not spoken to anybody about end-of-life issues before but wanted to, others coped by cutting themselves off from people, avoided the issues or were in denial.*

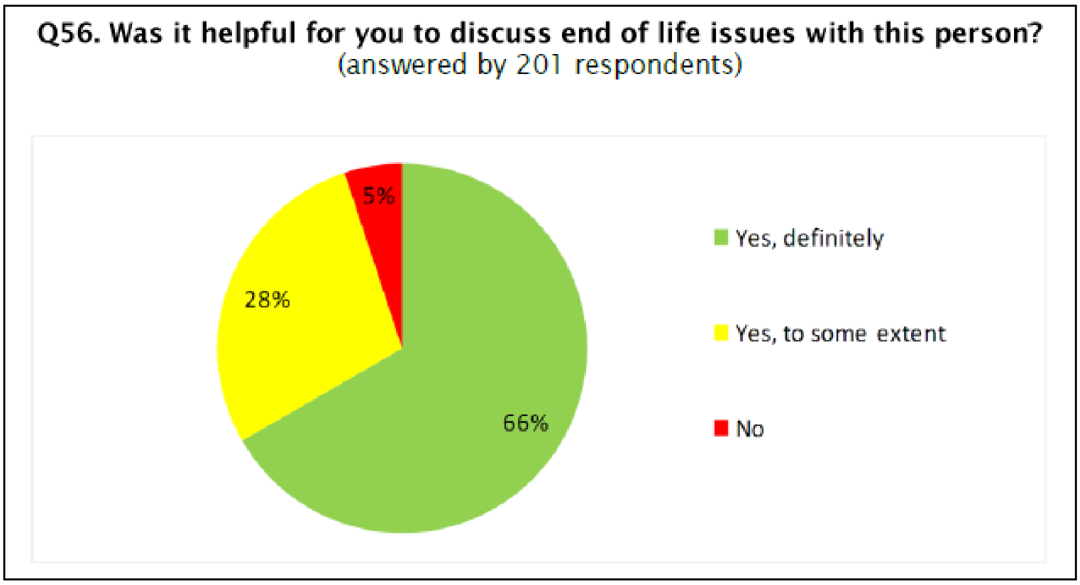
> *Several people said that these interviews were the first time they had discussed end-of-life issues openly with anyone. Although some of the questions were clearly difficult to answer and discuss, several people said they found it helpful to explore things in their own mind, with an impartial person rather than a family member.”*

In 2013, a third of respondents had both been given the opportunity to discuss end of life issues with a care professional, and actually did so. However, just over a tenth were **not** given the opportunity but would have liked to have had the opportunity. A third of respondents felt it was too early for them to have these discussions.

The 2012 researchers reported a perception, especially amongst male interviewees, that it was their responsibility to deal with the end of life alone and without showing their feelings.

> *“I’ve not discussed [end-of-life] with anybody including the wife, not because I don’t want to. When is the right time to talk about it? Maybe we ought to talk about these things more, probably just to make sure they’re clear in everybody’s mind as to what’s going to happen.”*
> *(male, face-to-face interview)*

Some people with MND are reluctant initially, and then slowly open up to having discussions. The 2013 findings suggest that overwhelmingly, having the conversation is a positive and useful experience.


Q56. Was it helpful for you to discuss end of life issues with this person?
(answered by 201 respondents)

We know anecdotally that some people are never willing or able to talk about end of life care, despite being given opportunities, and this should be respected.

Making plans

In the 2013 survey, two-fifths of respondents said they had already taken steps to ensure they have control and choice at the end of their life. Nearly half said they had not yet but they will. More needs to be done to ensure that conversations are followed up with written plans.

With up to half of people with MND experiencing some form of cognitive change, planning ahead is particularly important. While a third of respondents had made an advance care plan and/or decision, a third felt it was too early to do this, a tenth planned to make one and a quarter did not know what this was.

It seems that people with MND are very good at keeping their plans up to date once they've made them: almost all of the respondents who had an advance care plan and/or decision said theirs reflected their current views.

Place of death

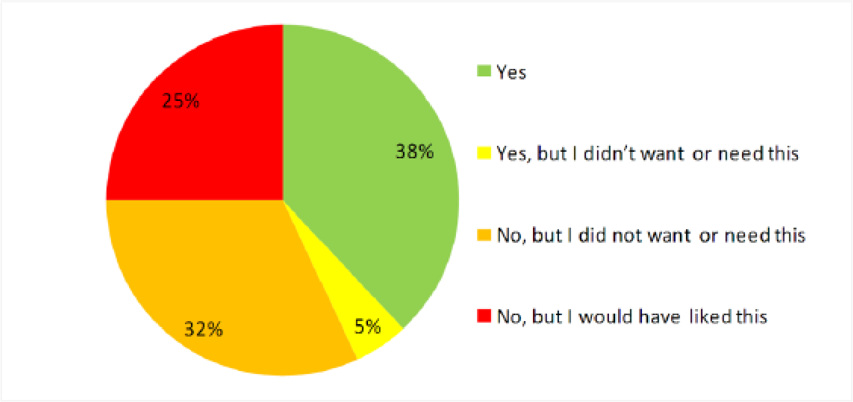
Having a choice of where one dies is important to many people with MND. Data are not collected on place of death amongst people with MND by government, and our own records are incomplete, so it is difficult to say where most people die currently. Anecdotally, we know a significant portion of people die in hospital. Some admissions are unavoidable, but many are not. We know that hospital is usually the least preferable place for people with MND to die, as this setting is simply not set up to care for people with such complex needs.

There seems to be a move away from place of death as an important choice people approaching the end of life and their families should be able to make, and see delivered, recently. This is a mistake in our view. While place of death does not tell the whole story, it can be a really important part of the person's experience. Despite recent improvements, preferred place of death is far from being delivered universally.

Access to information

Our 2013 survey found that a third of respondents were not given information about the choices and options available at the end of life but would have liked this. Two-fifths had been given this information.

Q50. Have you been offered any information about your choices and options at the end of your life?
(answered by 589 respondents)



Our response to this finding is discussed below.

What is needed to make choice a reality

Better access to information

The research we carried out in 2012 and 2013 identified a significant gap in end of life care information and advice available to people with MND and their carers. Our first ever comprehensive guide on end of life care for people with MND and their carers, published in May 2014, responded to, and aimed to meet, this need.

The full guide is attached as an appendix. It covers:

- the benefits of planning ahead
- how to communicate ones wishes, preferences and needs with family, friends and health and social care professionals
- how to access support
- how to put personal affairs in order
- information about medical treatments and what can be done if they are no longer helping.

The response to the guide has been almost entirely positive and it is clear that a significant demand has been met by it. For example, one person living with MND said

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

We have anecdotal evidence that professionals in a range of settings are using the guide themselves, to improve their practice.

Prioritisation by decision-makers

Although it meets an information need, our guide doesn't provide everything the person with MND and their family needs to make choices at the end of life. It must be paired with local information, advice, support and access to high-quality services.

Despite improvements in recent years, access to specialist palliative care services by people with conditions other than cancer remains very low.[1] Where people with MND have access to these services, we know they are extremely valued and have a significant impact on quality of life. This inequity of access needs to be addressed if true choice is to be delivered to all dying people.

Health and social care professionals must be motivated to improve palliative and end of life care practice, and given the space and incentives to do so. Commissioners must commit the resource required to make this happen. This includes, but shouldn't be limited to, extending access to specialist palliative care professionals. It should also include driving up standards

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[1] *National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2012-2013* (2013) The National Council for Palliative Care and Public Health England www.ncpc.org.uk/sites/default/files/MDS%20Report%202013_0.pdf

of basic palliative care skills amongst non-specialists, for example district nurses, neurology nurses and doctors, and care home staff.

Universal choice will only be delivered if there are central and local drives to prioritise palliative and end of life care amongst competing priorities in NHS and social care budgets. Although end of life care has benefitted from government funding and prioritisation in recent years (namely, since the 2008 End of Life Care Strategy), the move away from centralised drivers has led to some localities choosing to improve end of life care and other localities overlooking it entirely.

Investment in initiatives such as Electronic Palliative Care Coordination Systems (EPaCCS) are key to delivering choice, and should be prioritised centrally and locally.

Availability of social care

The lack of social care packages for people over certain income thresholds is a major barrier to complete, holistic care and choice at the end of life. As Mark Styles, who is living with MND in Kent, states in the Foreword of a recent report on access to non-means tested social care:

> *"Like many people living with a chronic degenerative condition, the care available to me towards the end of my life is a big concern. As my condition advances, I will rely on carers for all my basic hygiene needs, food preparation needs, movement, and use of vital equipment such as ventilation machines and feeding tubes. As these are social needs, their provision will probably be subject to a means test. As well as being time consuming and stressful, going through a means-test forces me, and thousands of others in my position, to use my limited life savings to pay for this basic care. As this report highlights, there is a huge variability in terms of who currently gets free end of life social care, who provides it and how it is co-ordinated"* [2]

Alongside NCPC and other charities, the MND Association continues to campaign for free social care, to make choice a reality at the end of life.

Appendices

Appendix 1 – *Improving MND Care: The experiences and views of people living with MND* (2013)) Picker Institute Europe for MND Association

Appendix 2 – *Choice and control when you have a life-shortening illness* (2012) Picker Institute Europe for MND Association

Appendix 3 – *End of life: a guide for people with motor neurone disease* (2014) MND Association

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[2] *How could free social care at end of life work in practice?* (2014) OPM www.opm.co.uk/wp-content/uploads/2014/06/How-could-free-social-care-at-end-of-life-work-in-practice.pdf

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