

Submission to the independent review of the use of the Liverpool Care Pathway

Introduction

- i. 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.
- ii. 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 of 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.

MND Association position

- i. The MND Association supports the Liverpool Care Pathway when used appropriately, and is confident that it can be used effectively and appropriately by palliative care clinicians familiar with MND. In September 2012 we signed a consensus statement supporting the use of the LCP, with over 20 other organisations.
- ii. We believe that continued use of the LCP is one of a number of mechanisms by which end of life care, and equitable access to end of life care, should be improved for people with MND. We also support the proposed development of an NHS tariff for end of life care, and non-means-tested social care for people at the end of life. Additionally, we support the recommendation of the All Party Parliamentary Group on MND that commissioners and providers should pay due attention to key guidelines (the LCP, the Gold Standards Framework and Preferred Priorities of Care) in designing and delivering specialist palliative care services.
- iii. We note that there have been numerous reports in the media of people being placed on the LCP without being informed, or their relatives told. These are undoubtedly of great concern, precisely because such action does not

constitute use of the pathway, which requires communication with patients and families. We hear consistently from palliative care clinicians that careful explanation of what is being done and why – and repetition of these messages to ensure they are understood and kept up-to-date – is essential. This is an integral part of providing high quality care to the patient and support for their family. Such misuse of the LCP is therefore of great concern, but it must be emphasised that practice of this sort does not represent implementation of the Liverpool Care Pathway.

- iv. Among the most concerning reports about alleged poor use of the LCP have been examples of people who have been taken off the pathway and who lived for some time afterwards, indicating that they had been placed on the pathway in error. Such instances are highly unlikely ever to occur in cases of MND. It is not unknown for people with MND to be taken off the LCP as a result of the regular reviews of the patient's condition that are required by the pathway, but this does not amount to the clinicians having made an error by placing the person on the pathway to begin with: MND is a complex and unpredictable illness, and precisely identifying end of life is not always possible with certainty. One of the LCP's strengths is that its use is revocable provided the patient's condition is reviewed as it should be. The terminal nature of MND should be emphasised in this context, however: even if a person with MND is taken off the LCP, there is no prospect of their long-term survival – MND is a fatal illness, and the end of life can certainly be anticipated, even if its timing cannot always be precisely forecast. We have received no reports of cases where the family of a person with MND felt use of the pathway was made prematurely.

Extract from 'Choice and control when you have a life-shortening illness' – Picker Institute Europe

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 people living with MND on end of life issues.¹ It is the first report of its kind: the extract below covers respondents' views on the process of dying; we believe it demonstrates that the correct use of the Liverpool Care Pathway is compatible with the views and wishes of many people living with MND.

'Peaceful' and 'pain-free' were words that recurred in discussions about the process of dying. Having a calm and pain-free death, surrounded by loved ones, was what many interviewees would choose.

Knowing that personal care needs would be taken care of and that they would not have to endure physical humiliation was also seen as vital for retaining dignity. Some interviewees felt that interventions were undignified and said that they did not want their life to be prolonged artificially;

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<http://www.mndassociation.org/Resources/MNDA/Life%20with%20MND/Documents/Choices%20and%20control%20FINAL.pdf>

“To me, dying with dignity means to be allowed to die rather than being kept alive by artificial means just because it can be done. Life may have been extended by a few weeks, but at the cost of stress to the person and their family.”

(female, email interview)

“[Dying with dignity is]...not being told what to do, not being interfered with and being allowed to stay in this house rather than being carted off to hospital and fitted up to a load of pipes and wires. I don't want to be a cabbage in hospital for my family to come and grieve over whilst I'm still alive.”

(male, face-to-face interview)

Many interviewees said that dying with dignity meant having control and self-determination – the ability to decide what happened and when it happened. Having a poor quality of life and being unable to do anything about it was seen as undignified;

“[Dying with Dignity means] to die when I feel that my life has no further purpose. Not to be kept alive when I can no longer communicate.”

(female, email interview)

“I think it [dying with dignity] is having choice over when and how you do die.”

(male, face-to-face interview)

Several people expressed the view that a ‘good’ or ‘dignified’ death meant having choices in terms of where to die, what interventions to have and which to refuse, at the right time for them. Several people made the point that it was up to each individual what was acceptable to them and what was not:

“I think dying with dignity is allowing [people] choices even if [their choice is] not to carry on.”

(female, face-to-face interview)

“Being helpless in every way is not ultimately dignified. Dying with dignity means choosing your own time and hopefully finding a reasonably painless way to die, in a place of your own choosing.”

(female, email interview)

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