mnda
motor neurone disease
association

Response to the proposed advice for health and social care practitioners involved in looking after people in the last days of life

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.

iii. End of life care therefore 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 dying and the end of life, and conducted the largest ever survey of people with MND in the UK on these issues. We will shortly publish our first comprehensive package of advice and guidance on end of life issues to people with MND.

iv. We welcome the proposed advice and opportunity to comment on it. While we feel there is little in the proposed outcomes and guiding principles to object to – in fact they usefully summarise what good care of people dying from MND should be able to expect - without strong implementation they will achieve little. . Whilst we do not advocate replacing the Liverpool Care Pathway with a similar tool, it should be remembered why the LCP was introduced and so widely used in England. Health and social care professionals not used to, or skilled in, caring for the dying need support to do so. While such professionals are unlikely to object to the guiding principles, having a document laying them out will not in itself help them to deliver good care in the last days and hours of life. If there is a sustained and well resourced programme of implementation, including education and training, standing behind the advice we would feel much more confident in the proposed approach. . If there is not, the standard of care available to dying people will deteriorate or, at best, not improve. We would like the Leadership Alliance to issue clear reassurance on this point, and set out the actions it will take as soon as possible.

v. Our response offers some observations on the proposals as a whole, then comment on more details aspects of them in response to specific questions in the consultation paper.

Practical improvement of end of life care

i. The discussion paper states that a programme of education and training will follow the initial exercise regarding advice and principles. This will be key: if it is sustained and properly resourced we would be optimistic about the prospects for improving care for dying people in England; if not, this may leave a vacuum in which standards will be allowed to deteriorate.

ii. The NHS End of Life Care Programme, now defunct, showed the benefits of this approach with its End of Life Facilitators around the country, working on workforce development; now, workforce development in respect of end of life care appears to be much more haphazard. We hope that the Leadership Alliance will address this.

iii. We also note that the guidance does not extend to commissioners, and that there appear not to be any strong incentives for commissioners to commission high quality palliative, end of life and bereavement care. They are not the subject of any outcome or outcome indicator in the NHS Outcomes Framework or Outcomes Indicator Set, for instance. So while it is right that the guidance recommends that the needs of bereaved relatives are assessed and met, for instance, care professionals simply cannot do this if the appropriate services have not been commissioned. Under the new arrangements, clinical commissioning groups which decide to prioritise end of life care make it possible for health and social care professionals to improve practice; CCGs which do not chose to prioritise it make it difficult if not impossible for significant improvements to be made, and at worst, cause hard-won improvements arising from earlier work to be lost. Guidance, and preferably incentives, for commissioners must also follow.

Guidance on end of life care

i. We feel that the engagement document presents a fair general articulation of considerations around end of life care, but it is doubtful that it constitutes guidance in any practically useful sense. The format of the advice is not such that it could be readily and routinely referred to by clinicians and care professionals during their work.

ii. While the advice says it does not preclude the use of specific tools, it does not recommend any, or act as one itself, which leaves open the prospect of poor quality tools being used by inexpert clinicians in some locations, or guesses being made about the correct approach with no reference to any advice. The NHS End of Life Care Programme promoted three tools as representing good practice: the Gold Standards Framework, Preferred Priorities for Care and the Liverpool Care Pathway. The difficulties encountered with the latter appear to have prompted the Leadership Alliance to ditch the idea of usable tools or guidance entirely. It is not clear to us that this represents a positive step; rather, it seems to risk end of life care again becoming a lottery.

iii. We appreciate that experience with the Liverpool Care Pathway made clear the dangers of formulating guidance of this sort into a tool that can be readily and easily used: such a tool can also be readily and easily misused. This is why we advocate a strong programme of training and education: a focus on competence, and clear education about how tools should be used, and why they are written as they are, should foster high quality care. Guidance and tools can be a useful part of this, though they are not sufficient on their own as the Liverpool Care Pathway showed. We are concerned, however, that the current approach features neither education nor usefully accessible guidance.

iv. Finally, we are concerned that the proposed approach features an unnecessary introduction of new terms and initiatives, most notably “Personal Palliative Care Plans”. Care planning and advance care planning already exist and perform the same function. New systems for holding and sharing palliative care plans are also almost certainly unnecessary: Electronic Palliative Care Co-ordination Systems already exist in some areas and address the same problem; much work has already been done to establish them. We strongly advise the Leadership Alliance to roll these initiatives out rather than attempt to reinvent them.

1. Do you agree with the proposed outcomes?
If not, how can they be improved?
We believe the proposed outcomes are sound; where we have concerns, they relate to how the outcomes will be achieved.

2. Are the guiding principles right and sufficient to achieve the particular outcomes?
If not, how can they be improved?
We believe the guiding principles are fair, and offer a few specific comments.

Under Outcome B, point 4, it is not clear why the word “monitor” appears in inverted commas; it appears to be a perfectly fair word to describe the activity in question.

Under Outcome B, point 6, it seems to be assumed that a person who can no longer swallow can also no longer express their wishes about artificial hydration, as no reference is made to seeking their views when possible. It may sometimes be the case that they cannot express their views, but it should not be assumed that this is not possible.

3. Do you agree that anyone who has a progressive life-limiting condition should be offered opportunity to develop, document, review and update a personalised palliative care plan, rather than a plan that focuses only on the last days of life?
We have long advocated that people with MND should be offered the chance to receive palliative care and start planning for the future very soon after diagnosis. We already advocate that all people with MND have a care plan (not specifically for palliative care, although it can be said that all care for people with MND is, in the most neutral sense of the word, palliative), and that this should be developed in close collaboration with the person with MND, and regularly reviewed. Advance care

planning should be a key component of this exercise, but we are unconvinced of the need to reinvent it as a “Personal Palliative Care Plan”. In practice, professionals skilled in co-ordinating MND care encourage and work with people to plan and document their future wishes through the process of advance care planning, but might choose to use different language with the person with MND and their family (a popular phrase is ‘planning for your future care’).

4. If you agree with the proposal to offer a personalised palliative care plan, do you agree with calling it a ‘Personal Palliative Care Plan’?
If not, what should it be called?
We would favour thorough and consistent promotion of existing initiatives and good practice, notably advance care planning.

5. If personalised palliative care plans are to be introduced, it raises a question of how and where this should be kept. If it is kept in the person’s home, he/she would be able to look after it more easily. However, it may delay the ability of health and social care professionals (such as a doctor, nurse or ambulance staff) to take appropriate action on behalf of the person if the professional is not able to easily get hold of the information when needed. Do you have any ideas for how to find an answer to this practical question?
This appears somewhat to be an attempt to reinvent the wheel: the Electronic Palliative Care Co-ordination Systems previously being rolled out by the NHS End of Life Care Programme provided a solution to this problem.

6. Do you have any other ideas or suggestions for how we can improve care for people in the last days of life?
We note comment has not specifically been invited on the explanatory material intended for patients. Generally we regard this as sound. One place where we feel the language could be improved is under Outcome B, where it is stated that, “you should be assessed regularly;” it may be preferable to use the formulation “your needs” or similar.

Recommendation 38 of Baroness Neuberger’s report, listed in Annex A, is that condition-specific good practice guidance should be used to back up the individual end of life care plans that are now to be used in preference to the LCP. It is unclear whether this means condition-specific guidance on end of life issues – though we infer that it does – and where this guidance will come from. Will NICE or another public body be required to produce it? Should patient organisations take the issue into their own hands and produce it themselves? How will such guidance be promulgated? The MND Association is very willing to assist in the production of such guidance in respect of MND, but we would be grateful for some clarification of expectations on this issue.

For further information contact:

Alice Fuller
Campaigns and Development Manager
MND Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG

Tel: 020 72508452

alice.fuller@mndassociation.org

December 2013