

# Response ID ANON-9YEX-1ART-7

Submitted on 2013-04-26 11:27:49.338112

## 1 What is your name?

**Name:**

John Kell

## 2 What is your email address?

**Email:**

john.kell@mndassociation.org

## 3 What is your organisation?

**Organisation:**

Motor Neurone Disease Association

## 4 Do you agree with the initial list of future quality standards proposed in the consultation document (pages 10 -11)?

Yes, all (move to question 7)

## 5 Which ones do you disagree with?

## 6 Why do you disagree with the topic/s?

**Why disagree:**

## 7 Are there any topics/titles that should be amended and in what way?

**Which ones/what amendments:**

None.

## 8 Are there any potential equality issues with these topics that may affect a particular protected characteristic group?

**Equality issues:**

None.

## 9 Are there any other topics you would like to see considered that aren't in the list?

**Other topics:**

Further topics are required to capture the full range of social care needs presented by people with motor neurone disease (MND), which has severely disabling effects. These could be broken down in various ways, but the issues we recommend for consideration (in whatever format) are:

- social care for people with rapidly degenerative conditions, including how to respond to fast and repeated changes in need
- social care at end of life (NB a quality standard on health care at end of life already exists)
- social care support in the community for people with serious physical disabilities
- social care support in the community for people with communication difficulties
- holistic social care (as opposed to task-oriented social care, the model on which many social care visits are currently provided).

## 10 What are the reasons for your suggestion/s?

**Reasons for suggestions:**

The adult social care system currently struggles to meet the needs of people with MND effectively. This is partly because of the ongoing crisis in social care funding, which leads to long assessment waiting times, short transactional visits, inappropriately low levels of provision and so on; high eligibility thresholds and ungenerous means testing also leave many people outside the social care system altogether. Guidance on best practice cannot overcome these problems alone, but it will take some years to develop this library; we hope that by the time it is complete, appropriate funding might be available to enable good practice to be implemented consistently.