

Response to the consultation on shared decision-making

1. 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.
2. 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.
3. We are concerned to note that what the consultation paper describes as "shared decision-making" is not an accurate depiction of the term as it is generally understood. Shared decision-making involves patients and healthcare professionals working together to set goals, select test and treatment options, develop personalised care plans and establish the self-management of care when possible. This approach is highly valuable in a disease as grave as MND: it can greatly enhance the experience of care, give the individual a sense of control, and reduce the feelings of isolation or helplessness that MND can often bring.
4. The Government's misconception of shared decision-making as meaning little more than a consumer-type model of provider choice – and we note the draft mandate for the NHS Commissioning Board makes a similar error – is therefore a dangerous distraction that risks holding back progress in the NHS towards true shared decision-making for years. We recommend that the Government revisits the issue and produces new proposals. Promoting and embedding genuine shared decision-making needs a cultural shift in NHS; the new proposals should focus on the proactive promotion of shared decision-making to staff and patients.
5. We have particular concerns about key aspects of the consultation paper. Firstly, it should not be assumed that GPs are always the key clinician with respect to care co-ordination. Specialist nurses and other health and social

care professionals can fulfil this role, and in cases of MND (in which GPs are seldom expert) usually do.

6. The consultation paper was also highly complacent regarding care plans. It cites a figure of 83% of people having conversations about a care plan, but we know that far fewer – maybe as few as 20% - actually have a formal care plan. While it is true that conversations are valuable and a formal plan may not be right for everyone, the number of people with care plans is undoubtedly too low. They are particularly valuable for complex diseases like MND where in order to be effective care must be co-ordinated between numerous professionals and across multiple disciplines. A stronger approach to care planning is needed.
7. The relevance of a consumer-type model of choice for a condition such as MND is limited. There are few treatments available, so choice of treatments and providers is of very limited use. Nor is it clear whether existing expert providers of MND care such as the MND Association's network of care centres will even exist under the new NHS framework – if the provider market fails, as is possible for a rare and complex condition such as MND – provider choice will be meaningless.

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