

## **Response to the Consultation on draft regulations and guidance for implementation of Part 1 of the Care Act in 2015/16**

### **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 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.
- iii. We offer general comments on the guidance and regulations below, and then comment on selected questions from the consultation thereafter; where we do not respond to a question, we have no evidence to offer nor suggestions to make for that item.

### **General Comments**

- i. The MND Association is part of the End of Life Care Coalition, from whom an additional response to this consultation has been submitted, and to which we would draw attention.
- ii. Along with our partners in that coalition, we would like to place particular emphasis on the importance of timeliness of the process for assessing, planning for and meeting care and support needs for people with terminal conditions. We believe it is vital that local authorities have in place a mechanism for identifying people who are at, or approaching, the end of life, and for accelerating the assessment of needs and delivery of support accordingly.
- iii. Separately, along with a number of other charities representing people with neurological conditions, we also wish to highlight the need for better recording of data by local authorities, particularly on the diagnoses of people assessed

in their area for care and support needs. We believe that possessing and sharing such data is a vital aspect of ensuring that adequate care provision is maintained, and in allowing local authorities to assess their services for impact and efficiency, and to plan for better services.

- iv. It is our view that without collecting such information, local authorities will not be able to meet their duty to make an accurate assessment of the needs of their local population and future demand, develop an appropriately skilled workforce, and, promote a diverse and quality provision of services for particular condition groups.

## **General Duties and Universal Services**

### **3. Is the description of prevention as primary, secondary and tertiary, a helpful illustration of who may benefit from preventative interventions, when and what those interventions may be?**

- i. We welcome the description of primary, secondary and tertiary prevention within the guidance. We would place particular emphasis on the importance of the reduce/secondary and delay/tertiary prevention descriptors. MND is a progressive condition: as time passes people with MND will develop more complex care needs. However, while high quality care and support cannot prevent those needs developing, well planned care can considerably ease distress and improve quality of life.
- ii. We believe that, as part of the duty on prevention, it is vital for local authorities be expected to anticipate and plan for future care and support needs.

### **5. Views are invited about how local authorities should co-ordinate and target information to those who have specific health and care and support needs.**

- i. MND is a condition of low prevalence, but which entails significant and complex care and support needs. Being diagnosed with MND will invariably result in a person receiving an overwhelming amount of information on healthcare, social care, support, benefits, housing adaptations and equipment – at the same time as coming to terms with a devastating terminal diagnosis. It is absolutely crucial that information on how a local authority can help meet their care and support needs is clear, concise and tailored to their needs.
- ii. It is our view that local authorities will need to access expert advice and guidance in order to sufficiently tailor information for people with specific needs.
- iii. The MND Association is currently working in partnership with the Royal College of General Practitioners to develop and disseminate information on the early recognition of symptoms and diagnosis of MND. We believe that a similar model could be adopted among local authorities and partner organisations to develop tailored care and support information. Although we recognise that individual local authorities can and should continue to manage care services in a manner that best suits their local community, we strongly

believe that the sharing of best practice – particularly with regards to specialised care needs – must be formalised within this guidance.

## **First contact and identifying needs**

**13. What further circumstances are there in which a person undergoing assessment would require a specialist assessor? Please describe why a specialist assessor is needed, and what additional training is required above the requirement for the assessor to be appropriately trained to carry out the assessment in question.**

- i. Although we do not make comment on further circumstances in which a specialist assessor is required, we emphasise at this point the importance of adequate training for assessors in general. This is particularly important for assessments of people with rare conditions, and/or conditions with complex care needs, such as MND, where knowledge of the condition is a prerequisite for an accurate assessment of need. Monitoring the training of assessors and creating a mechanism to ensure that, where an assessor has no experience with a particular condition they consult someone with the relevant expertise, is vital to ensuring the quality of the assessment process.

**18. Does the guidance adequately describe what local authorities should take into consideration during the assessment and eligibility process? If not, what further advice or examples would be helpful?**

- i. We welcome the guidance to local authorities on interpreting the eligibility criteria as clear and concise. However, we believe that there is a need for further guidance on interpreting the criteria in the case of people with progressive conditions.
- ii. The guidance makes specific mention of fluctuating conditions, and the need for an assessment to look at an adult's needs over a sufficient time period to ensure that they are all accounted for. We would strongly argue that a similar approach must be taken when assessing an adult with a progressive condition.
- iii. In such a case, we believe that a care assessment must be anticipatory in nature if it is to be of value to the person whose needs are being assessed. This is particularly true in the case of rapidly progressive conditions such as MND. For the majority of people with MND, symptoms progress swiftly, and so an assessment carried out as a snapshot of the person's current needs is unlikely to remain accurate for any substantial period of time.
- iv. Further, we remain concerned at the existing approach to case closures. People living with MND typically need to report changes in their needs relatively often. Currently, cases tend to be closed once an assessment has been made and support plan put in place; later reopening of their case will invariably mean the loss of a named contact, and, frequently, greater waiting times. We recommend that case files for people with progressive conditions

should not be formally closed, but rather remain 'active' to ensure that changes in circumstance can be assessed, planned for and met in a timely manner.

- v. Although we accept that it is difficult to instruct local authorities to carry out an assessment that would take into account all future care needs of a person, we do believe that the nature of a person's condition – and the needs that result from that condition – must be taken into account. We believe that, in the case of MND, it is necessary that an assessor takes account of the course of an individual's condition to date, and the likely progression of need over at least the short- to medium-term.

### **Person-centred care and support planning**

#### **43. Are the ways in which different Personal Budgets can be combined sufficiently clear?**

- i. We are concerned that information on Personal Budgets in general remains highly complex. We do not believe that, in this instance, it is sufficient for the guidance to exist to inform local authorities of how Personal Budgets can be combined. Local authorities will inevitably interpret the guidance with varying degrees of consistency; however, because the underlying information is so complex, we believe it is necessary for the guidance itself in this area to be more readily accessible to people with care needs, and for the Government to produce at a national level accessible guidance on the use of Personal Budgets.

### **Integration and partnership working**

#### **47. Does the draft statutory guidance provide a framework that will support local authorities and their partners to make integration a reality locally?**

#### **48. Are there any ways the guidance can better support cooperation locally?**

- i. We welcome the focus in the guidance on promoting cooperation among local service providers. We particularly highlight section 15.8 (d), *Delivery or provision of care and support*, as being a potentially important tool to achieving better outcomes with complex care needs.
- ii. The nature of MND means that the vast majority of people living with the condition will require adaptations and modifications to their home; all will require aids of some description. Yet experience from the people we represent shows us that home adaptations are not, on the whole, progressed as a key part of the local authority's duty of care. We would like to see even greater emphasis placed on the benefits of other local authorities agencies – particularly housing – being viewed as a key part of the care assessment and provision process.

#### **49. Is the description in the guidance of exceptions to provision of healthcare (which effectively sets out the boundary between NHS and local authority**

**responsibilities) sufficiently clear and does it maintain the current position on the boundary?**

- i. We note there is a wide divergence of opinions on the defining of the boundary between NHS and local authority responsibilities. We believe that the potential significance of inadvertently moving the boundary requires close attention, and would welcome further assurances regarding the legal implications of the approach proposed in the draft guidance.

**53. Could local authorities' duties in relation to housing be described more clearly in the guidance?**

**55. How could guidance on the legal boundary between care and support and general housing responsibilities be improved?**

- i. We believe that there is significant scope within the guidance for an improved definition of the boundary between care and support and general housing responsibilities. Further, we believe that the extent to which local authorities should consider housing – particularly the possibility of adaptations to a person's home – when considering their duties as defined by the act are not sufficiently clear.
- ii. The guidance makes clear that local authorities should consider housing as a key aspect of their duty to promote wellbeing of individuals with care and support needs. However, it is unclear to what extent local authorities can and should be expected to act upon this consideration.
- iii. For a person with complex care and support needs – such as those living with MND – suitability of housing is often an integral part of that person's care. People living with MND will typically need a large amount of medical and care equipment within their home. As their symptoms progress, they will have mobility requirements – and so require wheelchair accessibility at home. They may need adaptations to bathrooms, for instance to provide a wet room facility. They may require hoists, grab rails, stairlifts or through-floor lifts to enable them to have continued access to all parts of their home.
- iv. Our reading of the guidance as it currently stands is that making those adaptations is outwith the scope of a local authority's care and support duties. However, in our view ensuring appropriate adaptations are made should be seen as a vital component of meeting a person's care needs. To that end, we believe that the guidance requires further clarification on the circumstances in which a local authority should be expected to prioritise a person's housing requirements as part of meeting their duties under this act.

**Moving between areas: inter-local authority and cross-border issues**

**72. Do the guidance and regulations about ordinary residence disputes provide enough clarity to settle ordinary residence disputes between two or more local authorities? Are there other scenarios that it would be helpful for the guidance to consider?**

- i. We welcome the guidance and regulations about ordinary residence disputes. We are aware of an existing case of a person with MND who was assessed for and awarded continuing health care (CHC) funding, and placed in a care facility of a neighbouring authority. When the person was re-assessed and subsequently lost their CHC funding, a dispute emerged between the host local authority and the placing local authority over who bore responsibility for funding their ongoing care needs. We believe it may be helpful for the guidance to consider scenarios in which the funding stream and type of care and support function changes for a person who is ordinarily resident in a local authority other than that in which their care and support needs are being met.

**For further information contact:**

John Cox  
Policy Officer  
MND Association  
David Niven House  
10-15 Notre Dame Mews  
Northampton  
NN1 2BG

Tel: 020 7250 8449

[john.cox@mndassociation.org](mailto:john.cox@mndassociation.org)

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