



Response to the Centre for Ageing Better consultation on the draft evidence review scope on the role of home adaptations in improving later life

About MND and the MND Association

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.
- iii. There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. 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 groups, 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.

Introduction

- i. The MND Association very much welcomes this evidence review scope and the proposed focus on home adaptations and their role in supporting people in later life.
- ii. For someone with MND, timely and appropriate housing adaptations can mean the difference between being able to choose to live and die at home and being forced into residential or hospital care. Adaptations and equipment can help a person with MND to maintain a level of independence, to move around their own home even after their mobility has been severely impaired, and to continue to leave their home and participate in the community. This can help families to retain a sense of normality, and can significantly relieve pressures, both emotional and physical, on informal carers.

- iii. Without timely and appropriate adaptations and equipment, however, people with MND can be left trapped in their own home, or moved into residential care when they neither want nor need to be there. The kinds of cases that the Association has assisted with recently include a person who cannot get downstairs and relies on the ambulance service to take them to medical appointments, a person who cannot leave their home because installation of an approved wheelchair ramp has been severely delayed, and multiple cases where people living in unadaptable social housing cannot be re-housed because of lack of available accessible or adaptable stock.
- iv. We hope that the Centre for Ageing Better's evidence review scope will provide some valuable evidence about what some of the key barriers are to securing and delivering home adaptations, and good practice that can help individuals and organisations to overcome these barriers.
- v. We have limited our comments to questions one and four in the consultation document. We are satisfied that the proposed outcomes, costs and savings will capture important benefits of home adaptations, that the definition of home adaptations is clear and that the proposed literature to be included will yield good results.

Comments on the aim and review questions

- i. We believe that the aim of the draft scope is clear and well-focussed, and that the first and second review questions cover a range of useful areas.
- ii. The third question could be usefully rephrased to capture a wider range of barriers. The question of an individual's reluctance to make adaptations to their home is a useful one to explore, and the concern is well-articulated in the background to the draft scope.
- iii. Questions regarding other barriers are not addressed, however. We would like to see this question broadened to focus on what barriers exist to successful delivery of timely, appropriate and high quality home adaptations. This may include an individual's reluctance, but may also include issues of cost, whether it is possible to adapt a property, lack of information, availability of suppliers and waiting times for assessments and financial support.

Comments on the definition of the population group, and groups within that population

- i. The definition of the population of interest is useful, and recognises that while older people are the primary focus in this case, there may be implications for disabled adults of working age as well.
- ii. We suggest two groups within this population that we believe should be considered separately; people with progressive conditions and people with a terminal illness.
- iii. For people with a progressive condition, such as MND, there needs to be specific consideration of future needs as well as current when conducting an assessment

of a home and installing adaptations. Because MND will become progressively worse, and people with MND will experience loss of motor functions over time, what is appropriate at the time of an initial assessment may not be appropriate for the future. This is also a driver to ensure that adaptations are made in a timely manner; waiting until a person is no longer able to move around their home at all before considering and commissioning a home adaptation can cause significant emotional and physical harm to that person, and can have a cost impact on other services that have to deal with the results of such a delay.

- iv. For people whose condition is terminal, there are additional considerations about the most appropriate type of adaptation that can help them to maximise their quality of life at the end of life. Creative approaches and innovative housing solutions, such as modular adaptation pods if there is available land and if they appropriately meet a person's needs, may be more appropriate where time is a consideration. Where adaptations are arranged by a local authority, whether minor or major, systems need to be in place to ensure that the needs of people with a terminal illness are met as a matter of priority.

Conclusion

- i. We very much welcome the Centre for Ageing Better's focus on the importance of home adaptations and the difference they make, and believe that this exercise will provide some useful and valuable insight into current research and evidence.
- ii. We would particularly welcome any analysis of evidence specifically relating to groups of older people with progressive conditions and terminal illnesses, as we believe there are specific considerations for significant population groups that would benefit from examination. We would also welcome a broader focus on the barriers people face in securing home adaptations.
- iii. We welcome the opportunity to comment on this draft scope, and would be interested to be involved further in the future. We look forward to seeing the results of this engagement exercise and of the research itself.

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