

Written evidence submitted by the Motor Neurone Disease (MND) Association (CVD0026)

The effectiveness and accessibility of Government communications and consultation with disabled people during the pandemic

1. The Government's communications with disabled people during the pandemic have been of mixed standard. There have been efforts made by central government departments to engage with patient organisations in the voluntary sector, which has been welcome, and to draw on the sector's communication links with disabled people across the country. However, there have been issues with confusing and unclear messaging and a lack of centralised information resources, particularly around access to support for vulnerable people.

2. One example of this has been the confusion over the Government's extremely clinically vulnerable list of people considered highly vulnerable to the virus. The Government has produced advice for two groups, the clinically extremely vulnerable group (which was advised to take extreme shielding measures during the peak of the outbreak) and a wider vulnerable group (later referred to as the non-shielded vulnerable group). This caused a great deal of confusion for people living with MND, particularly after the Government's decision not to include all people living with MND within the clinically extremely vulnerable group.

3. Despite representations from specialist MND clinicians across the country, the Government's policy in England is to limit registration as extremely vulnerable to those people with MND with identified bulbar and respiratory complications. However, MND is a rapidly progressive condition with a median survival of only 17 months after diagnosis, and a median 8.7 months between first assessment and the development of respiratory symptoms. Many people with MND found it hard to understand why they had not been classified as extremely vulnerable, particularly as this appeared to contradict the advice of their specialist clinicians, and what this would mean for the support they could receive. There was also significant confusion about whether people with MND should undertake shielding and whether they would be supported to do so.

4. The Government's announcement that its shielding advice would come to an end in August has also been poorly explained. It has not published the scientific evidence behind the decision, nor has it clearly communicated the reasoning for its view that shielding is no longer necessary. This has led to a loss of confidence and trust in the Government's advice and a perception that it is not prioritising the safety of disabled people.

Disabled people's access to food and the effectiveness of the Government's response to reported problems

5. We believe the Government should have played a greater role in ensuring that disabled people understood and had access to the support available to them around access to food. The majority of food support has been arranged and delivered locally

through local authorities, with the exception of a limited central food box programme available only to people on the clinically extremely vulnerable list. However, there is no centralised online information resource to advise people how best to access food support through local routes. The majority of local authorities set up food support helplines, but again these numbers are not listed in any one place. Rather than relying primarily on local authorities and charities to disseminate this important information, the Government should have taken a more active role in collating key information on food support on an easily accessible central resource.

6. In addition, the restriction of priority supermarket delivery slots to members of the clinically extremely vulnerable list significantly limited the number of people who could benefit from this support. Many disabled people, older people and their carers, found that they could not get online delivery slots because they were not registered as extremely clinically vulnerable. This includes many people who took the decision to shield in order to protect themselves and/or vulnerable family members from contracting the virus. As the summer progressed DEFRA worked with supermarkets to secure some reserved delivery slots accessible through local authority referrals. This development was welcome, but for many people felt like too little, too late.

Disabled people's access to healthcare services, including treatment for COVID 19 and access to other healthcare services

7. In order to release capacity within the health system during the outbreak, a number of services have been reduced or delayed. This is a particular concern for people living with MND, a relentlessly progressive condition which requires ongoing monitoring of symptom progression and a wide range of service interventions coordinated through a specialist care team.

8. There has been a lack of clear communication of which services have been suspended, reduced or otherwise altered as a result of the COVID-19 crisis, and when they can be expected to resume. This is a cause of major anxiety and distress for people living with MND. The MND Association has heard accounts of a number of vital services being disrupted including:

- New initiations to non-invasive ventilation (NIV) have come to a halt. NIV is a vital intervention for many people living with MND as they develop respiratory impairment due to the progression of the condition.
- Face to face neurology consultations have largely come to an end, with consultants relying on remote consultations. These work well for some patients but can be very challenging for others, particularly those with digital accessibility needs.
- Palliative care is increasingly being delivered at home, which places a unique pressure on carers at a difficult time in their caring journey. Currently support to manage palliative care at home confidently is limited.
- We are aware that some hospices are unable to admit people with MND at the end of their lives due to the requirement for high-grade PPE for staff when caring for people using assisted respiration. Some hospices have been

unable to procure either the equipment or the necessary training for staff on its use, and as a result are excluding patients with MND.

- Rehabilitation services such as physiotherapy have been largely suspended.
- Home delivery of vital support equipment including wheelchairs and environmental controls have been largely suspended.

9. The lack of monitoring and clear communication of how services have changed and when they will aim to resume normal service is a cause of significant anxiety and confusion for patients, who are unclear how their needs will be managed on an ongoing basis. A survey of patients with neurological conditions by the Neurological Alliance found that 72% of respondents reported having had NHS appointments delayed, and 40% did not know when they would resume. 39% of people due to see a neurologist were not given an alternative date for their delayed appointment.

10. The NHS should record and publish the service changes that have taken place in order to ensure ongoing accountability and enable patients to understand how their health care provision has been affected and what alternative support arrangements are available. It should seek to resume normal service standards as soon as possible and provide a timeline for this to happen.

11. We have particular concerns about NHS Continuing Healthcare (CHC). Under the provisions of the Coronavirus Act, NHS providers can delay undertaking the assessment process for NHS CHC for people being discharged from hospital, until after the emergency period has ended. People who are discharged may instead have their out-of-hospital care funded by the NHS under a temporary emergency discharge protocol.

12. While this temporary measure was very welcome, there is currently a lack of clarity and consistency over how and when normal CHC procedures will resume. NHS England has produced no plans for lifting the emergency discharge procedure, and there has been significant variation between local clinical commissioning groups in how they have managed CHC during the crisis. Some have continued assessments and appeals almost as normal throughout, while others have suspended almost all CHC processes. This has caused confusion for patients and there has been very little guidance or information to the public from the Government regarding what they should expect of CHC services or when normal service can be expected to resume.

13. There will be a significant backlog of CHC assessments to be dealt with once those services fully resume. These assessments should be handled fairly and consistently across the country. The NHS has so far issued no guidance to CCGs on recovery plans, and no national template or guidance to ensure a consistent approach across the country. We would like to see the NHS at the national level take a much more active role in the provision of guidance and information to both the public and to local commissioners.

Social care for disabled people in their homes and in residential care settings, including the effects of easements to duties in the Care Act and the approach to monitoring and review of these changes;

14. We are aware that the Coronavirus Act made changes to the Care Act (England) and Social Services and Wellbeing Act (Wales) enabling local authorities to prioritise their services to ensure the most urgent and serious care needs are met, even if this means not meeting everyone's assessed needs in full or delaying some assessments, and temporarily relaxing local authority duties to conduct a needs assessment and prepare an adult carer support plan. At least seven local authorities enacted Care Act easements under these provisions. While it is difficult to monitor and understand the impact on people with MND within this short time period, we are concerned about the impacts of those easements being enacted, particularly as MND is a rapidly progressive, highly disabling condition which requires constant monitoring and ongoing care.

15. Many people living with MND have seen disruption to the social care services they rely on. This has come in many forms, including but not limited to members of their care team self-isolating due to contracting COVID-19, other members of their care team being redeployed and a lack of PPE. In some cases families have chosen to discontinue at-home social care to minimise the risk of contracting the infection.

16. Consequently the pandemic has been an exceptionally difficult period for unpaid carers, usually family members, many of whom are struggling with additional caring responsibilities during the pandemic as statutory services are reduced. In addition, caring for a person who is at increased risk of mortality from COVID-19 brings with it new concerns and issues to deal with, including access to appropriate PPE. The majority of people living with MND have taken extreme shielding measures due to their increased vulnerability to the virus. This means that carers and family members have also shielded as much as possible to minimise the risk of contracting the virus and passing it on to the person they care for. This has placed carers in extremely difficult and stressful situations- for example, weighing the risk of going to the supermarket (and possibly contracting the virus) against the need to provide food for a vulnerable disabled person. Carers have told the MND Association that they feel isolated and under enormous pressure; that it is not clear what additional support is available to them or how they can access it; and that changes to local services affecting them have not been clearly communicated.

17. Carers are holding their situation together as best they can, but we are aware of a wide range of issues and concerns affecting them, including:

- Feeling that they don't know where to go to for additional support
- Communication not working- no reassurance or proactive response
- Lack of PPE for unpaid carers and families when someone is discharged
- Discharges from hospital taking place without adequate support in place, increasing emotional and physical pressures on carers
- Reduction in respite care and support services

- Unpaid carers have chosen to refuse to allow care workers into the home without the provision of PPE in order to protect those they care for, resulting in care packages breaking down
- Feeling unable to access support for food provision, including priority delivery slots, and not knowing where to turn for this information
- Feeling concerned about making use of services again once they begin to reopen in case it still constitutes a risk to their loved ones.

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound, feeling etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.
- It affects people from all communities.
- Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.
- It kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is around 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- It affects up to 5,000 adults in the UK at any one time.
- It kills six people per day in the UK, this is just under 2,200 per year
- It has no cure.

About the MND Association

The Motor Neurone Disease Association is the only national charity in England, Wales and Northern Ireland focused on improving care, research and campaigning. We have over 9,000 members forming a powerful network that provides information and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments and brings us closer to a cure. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

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