

Motor Neurone Disease Association response: Health, Social Care and Sport Committee consultation on the impact of the Covid-19 outbreak, and its management, on health and social care in Wales

June 4th 2020

The Motor Neurone Disease Association welcomes the Committee's timely inquiry and is pleased to have the opportunity to respond. We believe the coronavirus outbreak and the Government's response to it will have a significant impact on people living with motor neurone disease (MND).

Social care easements: There is a great deal of concern regarding the amendments to the Social Services and Well-being (Wales) Act 2014 which relax the duties on local authorities to carry out needs assessments for adults and adult carers, meet adults' eligible care and support needs, and meet adult carers' needs for support. In particular, we are concerned about the lack of monitoring and accountability to ensure that any easements of duties are proportionate and necessary. While we recognise the need to increase the capacity of local services during the COVID-19 crisis, it is essential that there is clear public communication of any local authority decisions to reduce their social care provision, and ongoing monitoring to ensure that all easements are justified, proportionate and temporary.

Currently there is no clear communication to allow the public to understand which local authorities have chosen to apply easements to their duties under the Social Services and Well-being (Wales) Act 2014. There is also no clear system to provide ongoing monitoring of these decisions to understand their impact and ensure that they are necessary and proportionate. This compares poorly with the situation in England, for example, where there is a publicly available list of local authorities which have enacted easements to their responsibilities under the Care Act, and where the Care Quality Commission actively monitors these decisions in order to hold local authorities to account.

The lack of communication to people who need or are in receipt of social care, and their carers, is a source of enormous anxiety. The Welsh Government should develop a central communications resource to ensure public transparency on all changes that have affected social care provision, and should establish a system of ongoing monitoring of local authorities to ensure that all social care easements are proportionate, necessary and time limited.

Carers: This is an exceptionally difficult period for unpaid carers in Wales. Many are greatly struggling with additional caring responsibilities during the COVID-19 crisis 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 are undertaking extreme shielding measures due to their increased vulnerability to the virus. This means that carers and family members are themselves forced to shield as much as possible to minimise the risk of contracting the virus and passing it on to the person they care for. This places 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.

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 additional support
- Communication not working- no reassurance or proactive response
- Lack of PPE for unpaid carers and families when someone is discharged. No clear guidance in place from the Welsh government on when carers should use PPE and how they can access it.
- 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.

The Welsh Government should review the support available to carers during this enormously challenging period. It should provide clear communication and guidance on key issues of concern, including access to PPE, discharge arrangements for persons vulnerable to COVID-19, and the availability of wider support services at local and national levels. Carers have taken on an enormous responsibility during this period and it is essential they understand how to access the support they need.

Health services: 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.

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.
- 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
- Where people are cared for in palliative care settings, there is no clear Welsh Government guidance on visitation for family members and loved ones. The inability to visit people in their final days has a huge mental and emotional impact on family members and on the person affected.
- Assessments for Continuing Healthcare eligibility appear to have significantly reduced, risking the most vulnerable people going without essential care and support to which they are legally entitled.

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. The NHS in Wales 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.

Shielding: The Welsh Government elected not to add all people with MND to the extremely vulnerable list, despite MND being a terminal and rapidly progressive condition which causes significant respiratory and bulbar impairment. As a result, people with MND must be registered individually by their clinician. GPs have been asked to check the shielding list and remove people who do not meet the criteria. We are concerned that GPs will remove people with MND wrongly, as they are unlikely to have the latest information on an individual's progression. MND is a rapidly progressive condition which is primarily managed by a specialist care team. The Welsh Government must ensure that GPs contact a person's specialist care team to understand their current degree of MND progression before making any decision to remove shielding status.

In addition, there is confusion and uncertainty over the next steps for those who are shielding. As lockdown begins to ease, vulnerable people and their carers and families will face some very difficult decisions around managing the risk of contracting COVID-19. This is compounded by ongoing uncertainty over what measures will be in place to support people to manage that risk. A major cause for concern is whether carers and family members of people vulnerable to COVID-19 will be expected to return to the workplace, potentially risking contracting the virus and passing it on to a vulnerable person at home. The Welsh Government should issue clear guidance on the easing of shielding guidelines including anticipated timelines and detailing what support will be available to help the families and carers of vulnerable people during this difficult period.

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.

