

## **MND Association Briefing Summary: unpaid carers and Covid19**

The vital, underappreciated work that unpaid carers do is a long-standing concern of the Association. Due to the coronavirus outbreak, unpaid carers have been put under increasing strain and this has only been exasperated by the reduction and disruption of the health and social care system and the difficulties that social distancing requirements pose.

We are concerned about the combined impact on carers' health and wellbeing that increased pressure, numerous additional challenges, and a lack of extra dedicated support will have. There is a clear need for national and local government and others to act and do more to support unpaid carers during this time and going forward.

The worry and confusion regarding whether people living with MND can register as extremely clinically vulnerable or not has posed its own challenges to unpaid carers who will be supporting people with MND. Unfortunately, this will also impact on the amount of and type of care that unpaid carers are now needing to provide, as in some instances paid carers are unable to conduct the care they would normally provide.

There has also been a problem accessing supermarkets and food delivery slots for unpaid carers which has made it difficult for them to access essential supplies. Therefore, it is essential that the Government and supermarkets introduce new so that unpaid carers can still access food and other supplies. The government should develop a national registration/identification system for unpaid carers, which they could then use to access support unpaid carers alongside NHS and Social Care staff.

The Coronavirus Act 2020 suspends parts of the Care Act 2014, including the duty to carry out carer's assessments, the requirement to follow eligibility criteria, the duty to provide services, care and support plans, and it permits the prioritisation of care services deemed by the Local Authority as in most need. This support for carers that has been lost should be immediately reinstated and improved upon as well as further provision of further dedicated guidance for unpaid carers aimed at meeting their needs and if certain Local Authorities choose to relax measures to support unpaid carers under the Coronavirus Act, they should ensure there is other support available elsewhere.

Although we acknowledge the social care system is already overstretched and now under increased pressure due to Covid19, we believe the changes set out in the Coronavirus Act could have serious implications for unpaid carers and those they support. It is important that carers' rights are not being eroded when they are being relied on now more than ever and this should also be kept in mind when the Government turns to making future recovery plans

Unpaid carers are also likely to be experiencing increased financial difficulty during the coronavirus outbreak. The extra costs of caring are going to increase with the need to spend more on food, household bills (such as heating) and other essentials during this time. Therefore, paid care leave and flexibility policies should be introduced by the UK Government, and employers should ensure that their employees can be supported to remain in their job for as long as possible to help unpaid carers manage their work and care responsibilities.

The Association is pleased to see the Government has changed the eligibility criteria for Carers Allowance during the Covid19 pandemic but it is disappointed to see that there have not been any moves to increase the rate of Carers Allowance during this time, despite the increasing costs that unpaid carers will inevitably face and the additional pressure they are being placed under. Carers Allowance currently only provides £67.25 a week, which is the lowest benefit of its kind. This must be increased immediately, with a view to properly

reviewing Carers Allowance once the immediate response to the coronavirus outbreak is over.

Care workers are not wanting to visit people living with MND because they do not have the right protective equipment or feel they are at risk of passing on the virus and family members are not wanting to let paid carers into their homes without the correct PPE. The gap in care this creates is needing to be filled by unpaid family carers, which is increasing the strain they are being placed under and so we are calling for an increase in access to PPE for social care staff, including those paid for via direct payments and Personal Health Budgets

The Association is also concerned about the impact that the coronavirus outbreak will have on unpaid carers' physical and mental health. The Government should invest further in support services specifically for unpaid carers during this time as prolonged self-isolation and social distancing will have an impact on unpaid family carers. Carers will also have their own health needs and wider familial circumstances to manage, many of whom are needing to care for children who are now at home from school.

Unfortunately, some people with MND have already died after contracting Covid19. Carers may have had to deal with difficulties in end of life care provision and organising practical arrangements following their loved one's death. If the health and wellbeing of unpaid family carers are not sufficiently supported during this time, this could lead to a deterioration of the situation as carers burnout and increased demand is placed on Local Authorities and the NHS at a time when they are already struggling to cope with the impact of the epidemic.