

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

**Education Committee call for evidence: The impact of COVID-19 on education  
and children's services**

**MND Association response**

**June 2020**

1. The Motor Neurone Disease (MND) Association is pleased to have the opportunity to respond to the Committee's call for evidence. In this brief submission, we wish to draw the Committee's attention to an issue we feel has been overlooked by the inquiry's scope. We hope the Committee will still consider the Association's response.

**Key issue: Risk to a shielding member of family if children/adults within their household return to school/education.**

2. People with motor neurone disease (MND) are extremely vulnerable to the effects of Covid-19. MND is a progressive, terminal and highly disabling condition, which affects the respiratory system. There is a median of 8.7 months between first assessment and the development of respiratory symptoms and some people with MND have been advised by their clinicians that contracting the virus could prove fatal. Consequently many people living with MND and their families are undertaking extreme shielding measures. Many more who have not been directed to shield have been adhering to strict social distancing and hygiene measures, as advised by the Government for conditions that contain a higher risk from the effects of Covid-19.
3. We are aware of some families a member living with MND who felt no option but to remove their children from attending school, even before they were closed under lockdown, to protect their loved ones with MND from potentially contracting the virus. These families have also often had to refuse much needed care and support from services during lockdown where entry into the home has constituted too much of a risk. An incredibly large burden has therefore fallen on these families to try and cope under extreme measures, particularly falling on those who are unpaid family carers. For family carers who have been caring for a shielding person with MND, balancing their family's educational needs on top of their caring role and potential working responsibilities will have placed them under an enormous amount of pressure.
4. The Association is concerned that these efforts and hardships risk being undermined with schools re-opening as part of gradual lockdown easements. It remains incredibly important that people living with MND are still able to protect themselves from the virus, which will be made more difficult if their children return to school and begin interacting with others. Although we understand schools are undertaking measures to try and maintain social distancing, it is still a situation that will bring much worry to households that are trying to shield.

5. The Association urges the Committee to factor in these considerations and concerns as part of its inquiry, and push for a strategy and clear guidance for families who have been shielding.

**Key issue: the impact on children and young people from not being able to return to school due to protecting those who are shielding.**

6. Although the Association is concerned about the risk to a family member living with MND if children return to school, we are also mindful of the significant impact and long term effects that not being able to return to school will have on those children and young people who have been shielding with them. Their ability to learn and develop should not be impeded compared to children who are in a safer position to return. We anticipate that extra support will be needed for children and young people in this situation to feel confident that they are safe to return and not bring the illness home to infect those that they love. Failing that, extra provisions should be made for them so they can continue to learn and achieve while at home and protecting their shielding family member.
7. There have undoubtedly been social implications to living in lockdown for these children such as limited social development. Some may also be living in families in difficult financial circumstances where the family has perhaps had to cope with significant extra costs during the pandemic. Explicit support usually received through school or college may have not been available during this time, including safeguarding issues usually picked up by school. The impact on wellbeing should also not be underestimated, with many children likely to be living in fear of the virus. There may also be an emotional impact of living in isolation with someone with a terminal illness such as MND with no outlet to escape or re-focus, which school would have provided prior to the pandemic. Children and young people in a shielding household may have also had limited exercise opportunities, which can also have a health and wellbeing impact.
8. We anticipate that the availability of technology in households who are shielding may also be a key issue for learning and education. Many families will only have a limited amount of technology and devices to correspond and learn from, and this may be utilised by the person living with MND and/or a working parent.
9. The Association urges the Committee to consider that additional measures will need to be put in place to help children who have been part of a shielding family so that they can catch up with their education and deal with emotional impact.

**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.

### **Contact**

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