

TreatSMA
85 Great Portland Street
First Floor
London W1W 7LT

11th March 2020

Dear SMA Community,

It is a very worrying time for many in the SMA community with the recent outbreak of the coronavirus. Tensions are running high due to the uncertainty and how the situation is handled publicly by decision makers in this country. We accept that there are many opinions and different points of view and therefore it is impossible to offer a simple guideline to follow in such a fluid and evolving situation. We do believe that some analogy with other respiratory infections can be drawn and therefore some actions can be taken to reduce the risks.

Whilst the Coronaviruses family is known, the specific COVID-19 is a new strain and as infection numbers continue to rise the feeling of anxiety and concern within our community is very evident. We felt as a charity and more importantly as representatives of you all we should speak up, because that is what we are about.

We feel that the advice being offered currently to the general public does not take into account our SMA community; and that the advice could potentially lead to further harm if followed. Nor is some of it practical considering the complexed nature of the lives of people with SMA. TreatSMA has been waiting for our consultants to reach out to the community to begin offering more appropriate advice, but unfortunately we haven't seen anything done to reach out to any of us to offer guidance which is relevant to a community made up of children and adults with weakened respiratory systems.

We understand that clinicians and hospitals are to follow the advice and guidelines set out by our government, but as a charity we feel disappointed that those guidelines are not taking into consideration the specific impact this may pose for many of their vulnerable patients. Whilst we understand that there is no specific data to say that SMA people may be affected more than anybody else, we also do not want to take this lightly and would prefer to err on the side of caution.

For example, there have been many opinions that COVID-19 is no more dangerous than flu. Whilst there may be some truth, we must also remember that for the SMA community the common cold and flu is just as worrying and in many cases dangerous. We are all acutely aware how the SMA community is impacted by flu and the winter season pressures and limited NHS resources. In either cases, flu or COVID-19, a persons with SMA has the same



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chance of getting a infection as a person without SMA since the immune system is not compromised in SMA. However the consequences of getting a respiratory infection could be significantly different for those who have SMA due to the weaker chest muscles. Therefore it is important to follow your chest physio routine proactively to minimise any impact of respiratory infections. So at this stage we would also suggest provisions of relevant medical supplies are in place should there be a lockdown. This should cover your regular routine and a routine should one get ill.

There is currently no support offered to help parents with the difficult decision of whether to withdraw their child and/or siblings from school. This is currently left to the parents discretion, leaving those decisions to be risk assessed and interpreted by schools, who as we know unfortunately have limited knowledge of SMA. Likewise, there is nobody supporting adults with SMA who perhaps have questions around their working environment, how do they approach their employer about possibly working from home, extended sick leave etc. This also applies to working parents who care for someone with SMA.

In light of this TreatSMA has written a supporting letter for those who feel that themselves or their child(ren) should not be in an environment where catching the virus poses a risk for their family. For those who wish to act now - we are willing to support you. For those who wish to act later - we will still be willing to support you.

We know we are not medical experts, we aren't qualified to offer clinical advice, but what we are is a group of people who understand the concerns that you have, and are having to make the same difficult decisions that you are having to make. Everyone must act in the interest of the person with SMA and advice needs to be condition specific, as general advice being provided at the moment is insufficient to help people make decisions when faced with complex conditions such as SMA.

We hope that the suggestions we are offering would be supported by decision makers and suitable changes will be added to provisions. After all, the lives as well as the mental welfare of the community matter and the more support that is put in place the more we can act with peace of mind and clarity.

Yours sincerely

The TreatSMA Team