

To Whom It May Concern:

Subject: Please allow consultants to make the decision on whether a child needs to shield on an individual's circumstances, as well as whether shielding should include full families.

We are writing to you to express our concerns regarding the Governments' decision that children should remain off the extremely clinically vulnerable list, as well as the fact that consultants' hands are tied with this decision. They have to follow Government guidance rather than make decisions on an individual basis.

A recent study by the Spanish Society for Paediatric Neurology (Natera-de Benito, D., Aguilera-Albesa, S., Costa-Comellas, L. *et al*, 2021) demonstrated that Spinal Muscular Atrophy (SMA) patients were the most at risk of moderate symptoms and risk of hospitalisation after contracting Covid-19 when it comes to children with neuromuscular conditions. Out of 29 patients who contracted Covid-19, 38% (11/29) had SMA. Overall, 10% of patients were categorised as moderate and were hospitalised for an average of 7 days, one of which required admitting to the ICU – all of these patients had SMA. The conclusions of the study state "...it does not appear that SARS-CoV-2 infection is more life threatening for these children than other viruses such as rhinovirus or influenza." However, this quote is in regard to children with neuromuscular conditions as a whole, anyone who knows SMA knows that rhinovirus or influenza can be extremely dangerous for patients with SMA, often leading to hospitalisations.

This leads on to our next point, at a time when hospitals are over-run and resources stretched, it is imperative that patients with SMA are protected from *any* virus that could lead to hospitalisation, not just Covid-19. Also, if hospitalisation is required during this time, it is vital that the SMA Standards of Care are still followed, for example, only providing oxygen when it is fed through a bipap; our concern is that in a busy environment this could be overlooked.

Thirdly, it is felt that, in order to support the Government in their endeavour to stop transmission of Covid-19 and lower the need for hospital admissions by locking down, including closing schools, parents of children with SMA need more support in regard to time off work or reduced hours. Without a shielding letter, not all employers are forthcoming in this. It is felt parents who are frontline workers need support to be transferred to lesser demanding roles, or to be allowed to take paid leave. No one should be left in a position whereby they have to choose between keeping their job or providing their child the specialised care they need and protecting them from catching *any* virus that could lead to hospitalisation.

Finally, when schools do re-open, we are urging you to consider how pupils with SMA, *and their siblings*, will return to study. Many parents have found that, when schools reopened in September, they had support to continue home learning for their child with SMA, but not their 'healthy' siblings, meaning they are left with the choice of unauthorised absences, or sending siblings to school and risking them catching the virus and bringing it home to their sibling with SMA. The nature and set up of classrooms mean social distancing is not possible and, typically, classrooms are poorly ventilated meaning any viral load in such an environment would be seriously exacerbated. Would it be possible for pupils with SMA and their siblings to continue with online learning until the majority of the population has been vaccinated?

To summarise, we implore you to allow consultants to make the decision on whether a child needs to shield on an individual's circumstances, as well as whether shielding should include full families. This is due to the following reasons:

- A recent study by the Spanish Society for Paediatric Neurology (Natera-de Benito, D., Aguilera-Albesa, S., Costa-Comellas, L. *et al*, 2021) demonstrated that Spinal Muscular Atrophy (SMA) patients were the most at risk of moderate symptoms and risk of hospitalisation after contracting Covid-19 when it comes to children with neuromuscular conditions.
- At a time when hospitals are over-run and resources stretched, it is imperative that patients with SMA are protected from *any* virus that could lead to hospitalisation.
- Parents of children with SMA need more support in regard to time off work or reduced hours in order to provide their child the specialised care they need and protect them from catching *any* virus that could lead to hospitalisation.
- When schools re-open, we are urging you to consider how pupils with SMA, *and their siblings*, will return to study. Would it be possible for pupils with SMA and their siblings to continue with online learning until the majority of the population has been vaccinated?

We would appreciate a response addressing our concerns and queries in regard to consultants being able to make the decisions.

Sincerely,

TreatSMA

References:

Natera-de Benito, D., Aguilera-Albesa, S., Costa-Comellas, L. *et al*. COVID-19 in children with neuromuscular disorders. *J Neurol* (2021). <https://doi.org/10.1007/s00415-020-10339-y>



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