



9th July 2021

Dear Secretary of State,

Congratulations on your recent appointment. Now is the time to embrace the opportunity to improve the true wealth of the country and safeguard long term health.

We trust you are aware of the plethora of published research on the effects of COVID-19 infection and Long Covid on children.

Long Covid Kids is a grassroots advocacy & peer support group supporting over 3000 children with Long Covid, and membership continues to grow weekly.

Children may have experienced asymptomatic, atypical or typical severity of their initial acute COVID-19 illness. Members continue to experience chronic and disabling symptoms, unable to attend school, maintain friendships or enjoy their usual activities. Many have now been living for 16 months with what my own teenager describes as “a half-life.” Children have had little or no support, have not been believed and feel forgotten.

We urge you to consider the lived experience of children with Long Covid, and early evidence from researchers when creating policy. The health devastation of Long Covid on children is already impacting the workforce, creating poverty as parents lose their jobs while caring for children enduring unnecessary chronic health issues. Professor Esther Crawly, Professor of Child Health, Centre of Academic Child Health, University of Bristol, spoke at the Royal Society of Medicine Spotlight on Long Covid this week;

"Given the ONS data, I worry about a tsunami of Long-COVID in children. I think there is a real risk the NHS will not cope and affected children will not get the help they need which will impact on education and lifetime chances. We have a rapid access long-COVID clinic and demand already exceeds capacity"



We, therefore, urge you to support the families and taxpayers caring for children with Long Covid.

We welcome the recent announcement of the paediatric Long Covid hubs but would like to highlight that until there is a paediatric clinical definition for Long Covid, obtaining a referral is challenging and sporadic.

- Very few paediatric Long Covid hubs are operational yet;
- GPs contact us asking where they should refer;
- Families report that Long Covid is generally not accepted by primary care staff;
- Concerned families are being turned away multiple times without support. For those fortunate enough to find a listening ear, the advice given is more often outdated and potentially harmful. Comments like “try to do a little more each day” result in a subsequent high number of relapses, which are often worse than the initial COVID-19 acute infection.

Our urgent recommendations are as follows:

- **Provide urgent training for primary care staff** to enable assessment, support, and rehabilitation at the earliest opportunity to improve chances of recovery and likelihood of resuming education and joyful activities that promote wellbeing.
- **Protect the mental health and wellbeing of children and young people** by ensuring symptom reporting is documented and believed. We seek funds for additional research to achieve a clinical definition and understanding to improve the referral process.
- **Strengthen the work of NICE**, and issue guidelines to ensure all children who experience symptoms for four weeks or more can obtain a referral to the Long Covid hubs. Primary care staff commonly and inaccurately assert that they can not refer a child until after 12 weeks leaving families unsupported and fearful. There also appears to be an ongoing dilemma on whether young people should be seen by paediatric or adult services, leaving them unsupported and in limbo which needs resolving.
- **Utilise the lived experience.** We are encouraged by the newly announced commitment to supporting children via Long Covid hubs



and look forward to seeing their development and growth. By utilising our lived experience, alongside global research, we can improve the paediatric COVID outcome.

- **Implement a Long Covid patient registry**, to enable future evaluation of any potential long-term consequences of Covid-19. The prevalence of the relapsing and remitting nature of Long Covid continues to be consistent in children and young people infected in Spring 2020. What does their future hold?
- **Support the carers of children with Long Covid**. Children and young people infected in the first wave have now been ill for up to 18 months. Their carers are experiencing financial hardship as they pursue their career. Skilled workers are unable to return to the workforce. The government has supported the existing workforce. Preserving the health of the future generation is of equal importance.
- **Financially provide for the children and young people** learning to manage chronic and disabling symptoms. Long Covid is a disability. Children affected require carers and essential equipment for daily living. Families applying for Disability Living Allowance have been unsuccessful. One example of a reason given; “you don’t know long your child’s disability will last”.

Prevention

Since your appointment, you have stated that Covid cases could soon rise to above 100,000 per day, which would suggest at least 30,000 new cases of Long Covid per day.

The ONS data reports that of those who get COVID-19;

- 1 in 1000 for 2-11-year-olds will suffer Long Covid
- 5 in 1000 for 12-16-year-olds will suffer Long Covid
- 15 in 1000 for 17-24-year-olds will suffer Long Covid

9000 children have already had symptoms lasting more than 12 months.



The ONS figures are likely to underrepresented Long Covid in children due to the survey method that uses a list of just 21 symptoms and the relapsing and remitting nature of the condition.

The government has announced plans to lift restrictions, despite increasing numbers. Children and young people will likely be disproportionately affected by COVID-19, as schools, colleagues, and universities continue without appropriate mitigation. Most of these age groups remain unvaccinated. Israel is already reporting a shift in COVID-19 infections to an illness predominant in the young. The fastest increase reported in ages 10 - 19 years.

The only way to prevent Long Covid is to prevent initial infection.

We are calling on you to urgently:

- **Update the list of acute symptoms of Covid-19** to reflect the new variants and specifically highlight the full range of symptoms that children present with to allow families to apply for PCR tests and prevent transmission.
- **Acknowledge that children and young people develop Long Covid and protect them.** If you expect a peak of c.100,000 infections per day, many of which will be among young people, it follows that tens of thousands of children and young people will develop Long Covid. As stated this week by the Chief Medical Officer, "I think we will get a significant amount more Long Covid, particularly in the younger ages where the vaccination rates are much lower"
- **Offer vaccination to children with parental choice.** The MHRA has approved the Pfizer vaccine. Dr June Raine, MHRA Chief Executive "We have carefully reviewed clinical trial data in children aged between 12 to 15 years and have concluded that the Pfizer/BioTech COVID-19 vaccine is safe and effective in this age group and that the benefits of this vaccine outweigh any risk" Vaccination must be the priority for all UK children before children return to school in the Autumn term. Recent data reports that natural immunity is unlikely.



- **Reinstate mandatory face coverings to be worn in schools and crowded indoor spaces,**to reduce infections and improve the paediatric outcome.
- **Award grants to schools for robust mitigation measures to include; CO2 Monitors & Hepa Filtration to improve ventilation and air quality** in schools before the Autumn Term. The school holidays provide a valuable opportunity for preventative action.

We can not allow a generation of children to be exposed to unnecessary harm. Those already infected living with Long Covid are not being adequately supported and are at risk of reinfection. You have the power to improve the paediatric outcome and to make changes to help current sufferers. We implore you to do everything in your power to do both and to be a voice for children.

**Sammie Mcfarland Founder
Frances Simpson Co-Founder**

On behalf of the members of Long Covid Kids & all children

www.longcovidkids.org