

## Long COVID in children:

the perspectives of parents and children need to be heard

Parents have been struggling to obtain help and support, watching their children with persistent symptoms following acute infection with COVID-19. Early on in the pandemic, parents and children felt they were disbelieved by their GPs. As 'long COVID' came to be recognised in adults<sup>1</sup> and named as such by patients<sup>2</sup> there came to be a growing acceptance that it can also occur in children as evidence emerged.<sup>3</sup> Indeed, ONS data suggest that 12%–15% of children may have symptoms lasting 5 weeks after an acute infection with COVID-19.<sup>4</sup>

### SYMPTOMS OVERLOOKED

Lack of GP awareness has led to some parents whose children have long COVID feeling that their children's symptoms were minimised, experiences highlighted in the recent All Party Parliamentary Group (APPG) about long COVID in children on 26 January 2021.<sup>2,5</sup> Parents described desperation and fear of seeking further help, not wanting to be branded with the stigma of 'Munchausen syndrome by proxy.' While the adult population of long COVID sufferers were assembling on social media groups and collecting data, children were discounted under the misconception that they did not get COVID-19 severely, that they did not transmit COVID-19, and that they were often asymptomatic.<sup>6</sup> Even when the facts of paediatric inflammatory multisystem syndrome temporally associated with COVID-19 (PIMS-TS) in children started to present themselves,<sup>7</sup> it was understood that this was very rare. When parents started to wonder why their children were becoming ill from COVID-19 and not making a full recovery, there was no narrative to enable them to make sense of this.

Through desperation, mothers Frances Simpson and Sammie McFarland, whose children became ill in March 2020, joined forces to start the support group Long Covid Kids (<https://www.longcovidkids.org>). These families were told that there was no proof that their children's symptoms were a result of COVID-19, due to the lack of testing available in Spring 2020. Long Covid Kids has evolved to

provide support for families with long COVID; which now has 940 parents or carers, many of whom have more than one child with long COVID. Symptoms described by members of the group range from the most common; fatigue, headache, abdominal pain, dizziness, and muscle pain, to the most frightening; an electric shock-like pain in the eyes and head, nerve pain, testicular pain, liver damage, paralysis, and new-onset seizures; some of their experiences are captured in a film.

### SYMPTOM MISATTRIBUTION

Parents have noted that their children are also affected by anxiety, OCD, and volatile mood changes, which may be associated with neuro-inflammatory processes<sup>8</sup> as well as a natural response to being so unwell. The majority of parents would describe their child's symptoms as fluctuating, and many describe a gap of many weeks between the acute stage and the start of long COVID. This variability causes further confusion when presenting problems to a GP and often leads to diagnoses of anxiety or symptoms attributed to the effects of lockdown or home-schooling. The combination of an often mild or asymptomatic acute illness, followed by delayed, debilitating symptoms of long COVID, lack of testing, and limited awareness among GPs about the syndrome has meant that in the UK it is currently difficult to assess the prevalence of long COVID in children. The ONS data have now given some estimation and recent European data helps to validate this emerging condition in children.<sup>3</sup> As long COVID paediatric services evolve, it is hoped that GPs will be provided with the resources they need to support families where children are affected.

In consultations with parents and children it is preferable to admit to the limitations of knowledge while being interested in the experiences of the family, believing in presented problems, and offering support, help, and referral. Parents frightened for their child need to feel listened to, and the child needs their experiences to be validated. After all, their lived experiences are also valuable evidence.

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