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 disbeliefed by their GPs. As ‘long COVID’ came to be recognised in adults, and named as such by patients, there came to be a growing acceptance that it can also occur in children as evidence emerged. Indeed, ONS data suggest that 12%–15% of children may have symptoms lasting 5 weeks after infection with COVID-19.

SYMPTOMS 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 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. 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.

“Parents frightened for their child need to feel listened to, and the child needs their experience to be validated.”

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