

# Long COVID in children and young people:

## uncertainty and contradictions

### AN EVOLVING PICTURE

'Long COVID' describes both ongoing symptomatic COVID-19 (5–12 weeks after onset) and post-COVID-19 syndrome (≥12 weeks after onset).<sup>1</sup> Long COVID is also a patient-preferred term<sup>2</sup> so will be used throughout this editorial to describe symptoms lasting ≥4 weeks after an acute episode of COVID-19.

As the phenomenon of long COVID emerged and came to be recognised, including with the publication of the guideline by the National Institute for Health and Care Excellence, Scottish Intercollegiate Guideline Network, and the Royal College of General Practitioners,<sup>1</sup> there was still limited evidence about whether children and young people could suffer with prolonged symptoms following an acute COVID-19 infection. The general opinion was still that SARS-CoV-2 was a mild infection in the young.<sup>3</sup>

Narratives emerged, however, from parents describing prolonged problems in their children, following an acute COVID-19 infection,<sup>4</sup> and this was borne out in the scientific literature.<sup>5</sup>

Jasmin (young person with long COVID) describes her situation:

*'I'm Jasmin. I am 11 years old and I have suffered from long COVID for over a year. I was perfectly fit and happy, and enjoyed doing sports. Having long COVID has really changed my life in many different ways. I can't go to school much anymore, I don't see my friends, I can't exercise, I can't even walk far without a wheelchair. I think that a lot of people don't understand what the illness is and how difficult it is for me.'*

The prevalence of long COVID in children is disputed. Evidence from the CLoCK study,<sup>6</sup> which recruited a cohort of 11–17-year-olds from the general UK population between January and March 2021, gives a broad estimate. The study reported 66.5% of children had symptoms 3 months after a positive polymerase chain reaction (PCR) test, compared with 53.3% who had a negative

*"I'm Jasmin. I am 11 years old and I have suffered from long COVID for over a year [...] I tell myself that none of this is permanent even if it feels that way sometimes ..."*

test; 30.3% versus 16.2% had ≥3 symptoms at 3 months. The big limitation of this study was the response rate of only 13.4%. The researchers say that if this 13.4% is representative of all 11–17 year olds who have tested positive for COVID-19, over 32 000 (one in seven) young people throughout England would still have ≥3 physical symptoms 3 months later. However, if only teenagers who responded to the survey had any persisting problems and those who chose not to respond had completely recovered, this would mean a best-case scenario of 4000 cases of long COVID in children and young people.

The Office for National Statistics prevalence estimates indicate that 149 000 children and young people (aged 5–16 years) had symptoms lasting for ≥4 weeks after infection, 31 000 of whom have had symptoms for over a year.<sup>7</sup> The impact of the Delta and Omicron waves on these figures is yet to be determined.

### WHAT DOES LONG COVID IN YOUNG PEOPLE LOOK LIKE?

In the CLoCK study<sup>6</sup> the commonest symptoms described were unusual fatigue and headaches. Other studies suggest a broader range of symptoms,<sup>8,9</sup> including chest pain, anosmia, persistent cough and fever, muscle aches, gastrointestinal symptoms, anxiety, and low mood; and it is suggested that it may be difficult to differentiate some of these symptoms from the well-documented impacts of the COVID-19 restrictions on the mental health and wellbeing of children and young people,<sup>10–13</sup> particularly on the most vulnerable. In terms of mental wellbeing and quality of life, interestingly the CLoCK study reported no difference in the mental

health scores or wellbeing score between test positive and negative groups.<sup>6</sup> Magnusson *et al*, however, report that COVID-19 has had limited impact on healthcare service use.<sup>14</sup> So, the picture seems contradictory, but, as a recent editorial in *Nature* suggests,<sup>15</sup> further research is needed.

Jasmin's reflection demonstrates this complexity:

*'Long COVID affects my sleep and in the morning I always feel sick and achy. It affects my mood because I feel sad a lot of the time. When I exert myself too much, I can "crash". This means I have a very sore throat, stomach pains, swollen lumps in my neck, and aching legs and ankles. It feels like a very cruel illness because if I try and enjoy myself, I have to pay for it the next day. Long COVID makes me feel angry and sad, I have many mixed emotions, which can all be confusing.'*

While Jasmin's experience may represent an extreme end of what is a very broad spectrum of symptoms and severity,<sup>6,14</sup> GPs will encounter children and young people with a variety of presentations.

### NEGOTIATING RETURN TO NORMALITY VERSUS REINFECTION

The COVID-19 pandemic means that the environment in which we and our children and young people live in is ever-changing and hence challenging. At the time of writing, the Omicron variant is still spreading in the community. School offers a means of getting back to normality for most children, but young people with long COVID will need extra support to return to school.

Jasmin says:

*'I hope that there will be more support for people like me with long COVID to get back to school. I can go to school for a couple of hours, but I still need breaks. I find it hard to manage when there is lots of noise and I struggle to concentrate too.'*

School potentially, however, puts young

*"As with other unexplained symptoms, the invisibility of the illness [long COVID] must not be a barrier to offering adequate support, care, and management."*

people at risk of infection and re-infection, which for those with long COVID is a further threat. The impact of the vaccination programme on the risk of developing long COVID is not yet known, although a recent evidence briefing from the UK Health Security Agency reports some studies that indicate vaccination does reduce the risk of people developing long COVID.<sup>16,17</sup>

### WHAT DOES THE FUTURE LOOK LIKE?

It is not known whether all children with long COVID will recover and how long this will take. Parents' narratives suggest that symptoms can increase and decrease in severity, that symptoms may come and go, and that it is not uncommon to have a period of apparent recovery and then develop symptoms again 6 months later. Families report new symptoms over a year after infection, and that the course of the illness and 'recovery' are not linear.<sup>18</sup> This uncertainty is difficult for young people and their families to live with and compounds the direct impact of the condition on siblings and parents, including financial, when parents need to take time off work.<sup>17</sup>

Jasmin advises:

*'I would say, don't give up because that's the worst thing you can do. Just keep going and it's okay to be sad, it's okay to be mad because it can be a very depressing illness.'*

*I tell myself that none of this is permanent even if it feels that way sometimes, I am hoping that scientists will find a cure.'*

The varied presentation of long COVID, particularly the neuropsychiatric complications, can cause uncertainty for GPs, making the diagnosis difficult. Whatever this uncertainty for clinicians, however, primary care must play a key role in supporting young people with long COVID and their families,<sup>19</sup> liaising with schools where necessary. Importantly, children and young people need to be believed by their GP. At the time of writing, access to specialist long COVID clinics for children and young people is limited,<sup>20</sup> with only 15 hubs across England, so GPs have the primary responsibility of managing children with long COVID.

Jasmin has a final plea for GPs:

*'I would want GPs to listen to us and understand how serious the symptoms are, even if we look ok on the outside.'*

As with other unexplained symptoms, the invisibility of the illness must not be a barrier to offering adequate support, care, and management.

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