

## PATIENT'S VOICE

## Long COVID in children: Partnerships between families and paediatricians are a priority for better care

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'Damn sickness. I cannot believe that someone still does not believe it. The situation my son is experiencing must be a teaching one. People must know that even the youngest are involved'. Cosimo's voice is firm, but tired. Policeman, 46 years old, lives with his family in a small town in Southern Italy. His son, Giuseppe, is an 11-year-old slim boy. For 4 months, he has been fighting with Long COVID, the term accepted by the WHO to describe the medium- and long-term effects of Sars-CoV-2 infection in adults.<sup>1</sup>

Long COVID is now recognised by the international scientific community. A study published in *The Lancet*, carried out on 1733 patients in Wuhan, identified persistent symptoms in 76% of cases up to 6 months after diagnosis.<sup>2</sup> Countless studies independently confirmed these clinical findings in different countries. At the moment, however, there is a lack of in-depth data on childhood. Initially described in a small cohort of five children in Sweden,<sup>3</sup> a larger Italian study<sup>4</sup> and, more recently, an online survey in the UK<sup>5</sup> provided preliminary evidence of Long COVID in children as well. Nevertheless, these studies received criticisms, particularly on social media and national news channels: several people, including medical researchers, still think that these symptoms may be due to other causes, including the restrictions rather than the virus itself.<sup>6,7</sup>

### The Parents' Voice

'It all started on November 21. Giuseppe was not well and a classmate tested positive for COVID-19. Diagnostic tests confirmed Giuseppe's contagion'. But despite the subsequent negativity of the control swabs, Giuseppe never recovered. He had fever, shortness of breath, chronic fatigue, tremors, migraines every day. 'He was struggling to walk the home corridor – says his father – he had no energy. In recent months, he had enough energy to go out for a walk a maximum of five times'.

Blood tests, chest X-ray, spirometry, and heart ultrasound were repeated several times and always with the same result: negative.

'We feel a sense of disbelief and despair. We continually asked ourselves "What does Giuseppe have?" and we asked the same question to all the doctors we interacted with... The first to

understand the situation was our general practitioner: "Covid is certainly involved!" he said'. Subsequently a colleague hypothesised that Giuseppe's symptoms might fulfil the clinical picture of Long COVID and suggested to refer the child to a dedicated Long COVID paediatric service in Rome, Italy.

It is in this way that this group of paediatricians who take care of children with Long COVID met Giuseppe and his parents. They evaluated Giuseppe for the first time on March 5, 2021, the date that according to the family 'gave us hope after months of uncertainty and darkness'.

'Psychologically we are in pieces, but having a landmark we can count on, share our thoughts, and plan interventions gives us confidence. We've been through terrible months, with no answers. "Maybe I'm too protective", we said to ourselves. And then: "Only my son has this problem?"'. 'But no, we are not alone! Our son and, therefore, we too were taken care of by this group of paediatricians who have well explained to us how the Long COVID condition is a common condition for other children and young people who have had COVID-19 infection. He is carrying out a series of secondary level assessments and is taking an immunomodulator, after he made an extensive immunological assessment. He still has a low-grade fever, but he seems to be doing better. The desire to play and go out has returned, he gets less tired. It does not seem real to us after what we have been through'.

### The Paediatricians' Voice

Since the beginning of the pandemic, little has been said about the effects of the virus on children. However, as one of the group's paediatricians explains, a paediatric infectious disease specialist involved in International COVID-19 research projects: 'It is not true that they are not affected by COVID-19. We must pay attention to them because they have been forgotten during the all pandemic'.<sup>8</sup>

'We initially met Long COVID through adult works from our colleagues.<sup>9</sup> Then, working with an International team and the ISARIC, we have developed an international survey, now being tested in several European countries, aiming to assess if children as well are having Long COVID. Looking at the data from the first phase of the study, it struck us that although the survey was administered on average 160 days after the initial diagnosis of the virus, up to one-third still had one or two symptoms, a quarter at least three'.<sup>4</sup>

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Cosimo Fusco is the father of the *Long Covid* child from Potenza, Italy.

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'We were impressed that almost 50% of the patients interviewed complained of complaints after more than 120 days from diagnosis. In detail, we have seen that respiratory problems, muscle and joint pain, headache, insomnia, skin rash and palpitations were found in 3–20% of the total children. The social, emotional and educational impact is certainly significant. The most interesting fact was that the symptoms were also found in those with an initial diagnosis of asymptomatic COVID-19, but especially in those who had had a mild form and did not require hospitalisation. This confirmed what was observed in adults'.

Despite the clear evidence of Long COVID in adults, and the increasing description in children, there is still a lot of resistance in accepting it in children. 'This particularly worries us because more and more families are left alone, labelled as "psychological issues." During the last months, we have been contacted by several parents' organisations in Italy, UK and, more recently, Sweden'.

'We are grateful we have been in contact with so many patients' organisations, which really helped us understand the suffering and struggles of patients with Long COVID. It is not by chance that such a subtle condition received the deserved recognition thanks to the fights of patients themselves.<sup>10</sup> However, parents are now starting the same fight to let the scientific community understand the needs of their children who suffer with persistent symptoms since the initial diagnosis of COVID-19'.

We understand that, on a superficial glimpse, these symptoms may be confused as psychological constraints. However, with a thorough examination, a careful collection of the medical history and with specific evaluations, we are easily seeing that the lives of these children suddenly changed after COVID-19 diagnosis, and seldomly psychological issues were present before it. We must understand Long COVID and recognise its impact also in the paediatric age. It is our duty to investigate, to seek the pathophysiological basis of Long COVID, because only in this way will we be able to give answers to these families. Ultimately, children will benefit from this journey of partnership between families and paediatricians.

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