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Cite this as: *BMJ* 2024;386:q1664

<http://dx.doi.org/10.1136/bmj.q1664>

Published: 25 July 2024

We can do better for young people with long covid

We need greater awareness, resources, and rehabilitation for children and adolescents with long covid

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Research and resources to support children and adolescents living with post covid-19 condition (long covid) are sparse.¹ Difficulties with diagnosis, non-specific symptoms, and a lack of awareness are just some of the reasons for this,² and they contribute to the stigmatisation of this relatively new condition. Greater support, treatments, and resources are needed for young people living with long covid.

Global prevalence estimates of long covid in children vary widely depending on cohort, methodology, and definition, with reported rates of 1.6-70%.³ Obtaining a diagnosis can take time as investigations are needed to eliminate other possible disease cause, and symptoms can be broad and fluctuate or relapse over time. Symptoms of the condition include fatigue, exertion intolerance, mood changes, sleep disorders, headache, pain, and change in respiratory function and can affect everyday functioning, such as eating habits, activities of daily living, physical activity, behaviour, academic performance and school attendance, and social interactions.⁴

The nature of the symptoms, a lack of professional awareness, and absence of a definitive diagnostic test mean that stigmatisation is common. Young people with long covid frequently feel embarrassed about having the condition and its physical limitations, and that people behaved differently towards them because of misinformed notions that they might be exaggerating or that long covid is not a real disease.⁵ It has been suggested that stigma drives people away from health services, contributes to psychological distress, and compromises long term physical outcomes.⁶

The latest data from the UK Office for National Statistics estimated that more than 100 000 children and young people aged 3-17 living in England and Scotland were experiencing self-reported long covid in the month period ending 7 March 2024.⁷ More than 20 000 of these children and adolescents reported that their ability to undertake daily activities had been limited “a lot.”

Appropriate medical screening, rehabilitation, and assistive technologies can support those living with long covid by improving physical, mental, cognitive, and social functioning to perform essential everyday tasks such as self-care, communication, or mobility. Evidence based resources from the World Health Organization, produced with the long covid kids’ youth advisory panel, are available on this topic, and provide guidance on subjects such as pacing activity, managing breathlessness, and returning to education.⁸ Rehabilitation and assistive technologies can help improve participation in family life, education, and employment.

Even considering the high variability in estimated prevalence rates, the large number of covid-19 infections in children and adolescents means that large numbers will also develop long covid, many with debilitating symptoms with undetermined duration. Consequently, actions are needed to specifically target this population group to optimise their health and participation.

The UK based Long Covid Kids charity,⁹ dedicated to representing children, adolescents, their families and caregivers, continues to play a crucial role in raising awareness, enhancing understanding, facilitating early diagnosis, and improving interventions for this condition. There is a pressing need for further efforts and funding from all stakeholders to identify, treat, and support young people living with the condition to offer them the best possible opportunities for enjoying a full and active life.

We need research on the pathophysiology and clinical understanding of long covid and representative population data for the purposes of monitoring and future service planning to ensure that it is accessible. Biomedical research trials are an essential step to provide hope for these families as well as valuable insights for shaping clinical management guidelines and the development of targeted resources and treatments for this population.

Communication efforts need to focus on empathy, support, and validation for patients, whose voices should be included in conversations around long covid. Awareness campaigns are essential to ensure health professionals are informed of the importance of remaining open to the possibility of a long covid diagnosis. Training for health professionals is necessary to provide condition specific, comprehensive, multi-professional paediatric assessments and treatments, which includes rehabilitation professionals. These assessments must include screenings for post-exertional symptom exacerbation and postural orthostatic tachycardia syndrome. Treatment and rehabilitation plans must be personalised and supported with flexible or hybrid academic support for children and adolescents during their recovery or period of illness.

These recommendations aim to tackle children’s and adolescents’ immediate needs, but also considers the long term approach needed for the condition, and crucially, to raise awareness and understanding of this new and often stigmatised condition.

Contributors: Justine Gosling and Sammie McFarland conceptualised this article and wrote the original draft. Catherine Smallwood provided inputs while Natasha Azzopardi Muscat, Tomas Zapata Satish Mishra and Cathal Morgan supervised and provided contributions.

BMJ: first published as 10.1136/bmj.q1664 on 25 July 2024. Downloaded from <https://www.bmj.com/> on 11 April 2025 by guest. Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Competing interests: No declarations of interests to declare from any author except CM who is an Irish government appointee as a non-executive board director to the NDA, an Irish statutory body that advises the government on policy relating to disability.

Provenance: not commissioned, not externally peer reviewed.

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