

VIDEO THREE

THE IMPACT OF LONG COVID ON EDUCATION AND THE FAMILY

SCRIPT

Welcome to the Long Covid Kids Educational Toolkit.

Video 3 - The Impact of Long Covid on Education and the Family

Samir, 13, Long Covid

Video Transcript of Samir (Samir is a white boy, 13 years old with an English accent. He sometimes stutters slightly when talking. He has dark brown shoulder length curly hair. He is wearing a black T-Shirt and is sat on a brown sofa)

"I've been out of school for a very long time, I've missed the entirety of this school year. Online, using zoom, I have two tutors, one for English and one for Maths. Every week I try to have a half an hour session of each, but I barely manage to do that. The pain clouds my mind so much I can barely concentrate on the lessons, and the majority of the time I can't do the full half an hour. For the English I used to be writing the answers in pencil, that just took up way too much energy so now I use a whiteboard, a digital whiteboard."

In the last video, we looked at how we can support the health of children living with Long Covid and their participation in education and school life.

We also explored some alternatives for those who need additional support.

In this video, we consider the impact of Long Covid on education and the family. During this video, we refer to preliminary data findings of several surveys, developed in partnership with The University of Derby, which we plan to publish.

More information is available in the handbook that accompanies this series.

Educators have a unique role in the lives of children and their families, providing the opportunity to develop a strong and secure relationship with the children they work with. Educators are often the first to notice something is wrong, and are among the first to offer support. Having a child with any complex health condition can be challenging, especially when a condition is poorly understood.

It is normal for families to need time to come to terms with change in their child's health. Families report changes in health, and or, a new diagnosis can feel overwhelming and isolating. Educators should be aware of the challenges faced by families navigating Long Covid.

Our Health Experiences survey found that obtaining a diagnosis and accessing services requires time and effort.

Families reported a wait of up to 6 months to be seen by secondary care. Over half of the respondents reported they were very dissatisfied or dissatisfied with the level of care they received.

It will take time to research treatment options and for those treatment options to become widely available.

Although there is no cure for Long Covid it is possible to treat and manage some symptoms and for improvements in day-to-day function to be made over time.

Further investment in appropriate and accessible Long Covid services is an immediate priority.

Sharon, Mother of "K", age 13 at infection, now 16, Long Covid

Video Transcript of Sharon (Sharon is a white woman, she has long blonde hair worn down and in this video she is wearing a white shirt and also a pink top).

"She was tired all the time and just wanted to stay in bed. I'll be honest, for months I blamed lockdown, and hormones for turning her into a lazy teenager. When she started getting heart palpitations, constant headaches and feeling sick all the time and felt dizzy, I blamed it on anxiety and not drinking enough water. My daughter had said the hardest part of Long Covid is not being believed. I have to live with the fact that I was the first of a long line of people that she had to convince, including her GP, teachers, her paediatrician and other healthcare professionals. It's hard enough to be ill and to have your whole life turned upside down, but to not be believed by the people who should be there to help and support you, to the point you even start questioning yourself is the hardest thing of all about Long Covid.

Her symptoms were only acknowledged as Long Covid after her second infection in April 2022, where we had a confirmed positive lateral flow test and her symptoms significantly worsened leaving her pretty much bed bound.

At least this time we had an infection confirmed by lateral flow test. I thought this would help the process along as the connection to COVID was indisputable, but this changed nothing as still no one knew what to do, so they did nothing. My daughter was eventually referred to the Paediatric service. After a long wait to be seen, we were discharged after just a ten minute consultation where her symptoms were dismissed as being caused by anxiety. She was only reviewed again after I put in a complaint to PALS. Over the past two and a half years it has taken to get a diagnosis, I have had to write countless emails, put in several complaints, just to get her symptoms taken seriously. All the way along everything has been led by me, by my research and me constantly pushing for help. When I presented the GP practice with the clinical pathway and referral forms for the Long Covid service, they had not even realised they existed. After two and a half years of constant battling, misdiagnosis, gaslighting from healthcare professionals, tears of frustration and worry, we were finally seen by the Long Covid clinic in November 2022, where "K" received her formal diagnosis of Long Covid. Our journey towards getting a Long Covid diagnosis has been a long and difficult one, and once we got it, we were to discover that it changed very little, except to finally feel part of a community battling for the same end goal, so at last we were no longer alone on this journey.

She has now been out of education for a year and a half. She is 16 and not even had the opportunity to start her GCSEs. She is a bright child who loved school, loved to learn and feels she has had her whole future taken away from her."

Families can feel a range of emotions that may include feeling:

- a sense of loss of their child as they were before Long Covid, or feeling a sense of loss on their behalf for the experiences they miss out on
- a sense of injustice and question why this is happening to their child
- and lastly, guilt and wonder if they are doing everything they can or whether they should be doing something differently.

In addition to managing symptoms, families can experience bullying and stigma; especially those taking sensible precautions to reduce their risk of COVID reinfection or any other virus. Sensible mitigations include:

- wearing a well-fitting mask
- being cautious in poorly ventilated indoor spaces
- requesting that windows are open in classrooms to improve ventilation
- and last of all, asking for information about the steps your school is taking to reduce risk.

Reducing the risk of infection and reinfection is a priority for all children, as we don't yet know why some children will develop Long Covid or how long it will last. Our Reinfection Survey found that reinfection worsened existing Long Covid symptoms in 58% of children.

Long Covid can impact relationships and work. More than 40% of the Long Covid Kids Health Experiences participants indicated that their child now needs 'a lot' of care, whereas 92% of participants had no additional care needs before experiencing Long Covid.

These changes can place additional practical and financial pressures on family households.

Long Covid can impact friendships. Children report that they feel lonely and left behind.

Families report that talking to others who understand and are going through a similar experience can be helpful.

Liz, 17, Long Covid with PoTS

Video Transcript of Liz (Liz is a white teenage girl, 17 years old with an English accent. She has brown hair tied back in a ponytail and she is wearing a pink and red fleece top)

"Long Covid affects my relationships with people as well as how I present myself to the world. I have to use a wheelchair if I leave the house, I struggle to go anywhere at all, I have to have my mother push me. I only seen friends three times max over the last three years, and it's different for them as well. I'm treated differently, because of my disability, and it's not their fault but there's not enough awareness. And how people treat you differently because you are disabled as well really affects my life, because if I go out in public I get stares which is really uncomfortable for me, I struggle to anything at all so I have to rely on my mother all the time, and it makes me feel quite like I'm not doing enough. I can't go to school, so I'm not learning anything. And I've lost everything that meant something to me, 'cos I can't even read a book. I can't read, I can't go to school and I was academic, I used to be a skier, and a competitive skier, and I can't even do anything sporty. I've lost my identity, Long Covid has stripped me of my identity, and I've become... rely so much on my parents that I feel almost like I'm burdening them all the time and it's quite hard."

Solutions

Demonstrating empathy and flexibility can help strengthen the relationship between school and home:

- provide clear information about steps your school is taking to mitigate risks
- put in place appropriate support arrangements and make reasonable adjustments
- and finally recognise the need for flexibility [Images on screen saw 'Clear Information' 'Eating Lunch Outside,' 'Open Windows' 'Support Lessons' 'Air filtration']

Encourage families to seek support from friends, family, peers or counsellors. Within school, Emotional Literacy Support Assistants, Thrive Practitioners or Home/School Link Workers (or local equivalents) can support children and young people and their families.

Long Covid Kids provides signposting to services and offers peer-to-peer support for children and their caregivers.

Rhonda, Mother of a 15 Year Old Boy now recovered from Long Covid

Video Transcript of Rhonda (Rhonda is a Chinese woman with a Brummie accent. She has short red hair and is wearing a blue top).

"Having a child with Long Covid is one of the scariest things for a parent. When they are sleeping because of intense fatigue, you go in to check they are still okay, they don't even wake up enough to eat their meals. The only thing that kept me going was Long Covid Kids group, which I am so so grateful for, thank you."

Hierarchy of Needs

As educators, it is important to keep in mind that a child's health may need to become the primary focus for a period of time.

Enhancing a child's overall well-being may need to take priority over attendance and learning. Maslow's hierarchy of needs can help us understand this as it emphasises that children's basic needs, such as their physiological needs and feelings of safety and belonging, need to be met before we can expect them to be able to learn and reach their potential.

Learning to live with a complex health condition can come with a lot of can't-dos, so focusing on what the child can and wants to do is important for their mental health and well-being.

Support

Finally, it is worth recognising how family members, including siblings and extended family, are experiencing this process too.

It can be helpful to create a support system within the school community, where siblings, caregivers, and extended family can connect with others who are going through a similar experience, and signpost to local carers and young carers resources where appropriate.

Hannah, Family Member of two children with Long Covid

Video Transcript of Hannah (Hannah is a young white woman, with an Irish accent. She has brown hair worn up and she is wearing a white crochet top)

"I have two kids in my life, family members, who have been affected by Long Covid. They developed it, they've had COVID three times, they developed it in August of 2021. My niece, who I'm particularly close with, used to be able to swim, dance, do drama. She had ME before she got diagnosed with Long Covid, now she can't even attend a simple sleepover, without having a bad crash afterwards."

Summary

Long Covid can impact all aspects of life for the child or young person including their health, attendance and inclusion at schools, and friendships.

Likewise, it can have a significant impact on the whole family.

By understanding the emotions the family as a whole may be going through, we can provide the support and resources they need to navigate this burdensome journey.

Together, we can create a supportive environment where families feel heard, understood, and empowered to advocate for their child's well-being, to facilitate the best possible recovery outcomes

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In the next video in this series, video 4, we will share practical ideas to support children and young people living with Long Covid with their learning.

Video 3 Run time (15 minutes)