

# VIDEO ONE

## AN INTRODUCTION TO LONG COVID IN CHILDREN

### SCRIPT

Welcome to the Long Covid Kids Educational Toolkit.

Video 1 - An Introduction to Long Covid in Children

\*\*\*

Caitlin, 12, Long Covid

Video Transcript of Caitlin (Caitlyn is a white 12 year old girl, with a Scottish accent. She has brown hair worn down and falling just below her shoulders, and she is wearing a pink top)

"My personal Long Covid symptoms are leg pain, tummy pain, chest pain, brain fog, head pain, fatigue, breathlessness, lightheadedness and pins and needles."

\*\*\*

In this series of videos, we will be talking about Long Covid in children.

The training videos will increase awareness and understanding among educators. By the end of this series, teaching and support staff working in all age sectors will have:

- increased awareness and essential knowledge of this complex health condition.

These videos will empower educators to support children, young people and their families, including:

- When and how it is appropriate for children to return to education
- How to support children to access their education, be included and achieve their potential.
- When to consider alternative provisions and what alternatives are available
- And finally, how to find further support, how to signpost and make referrals.

\*\*\*

Let's start with some facts about Long Covid.

Long Covid is an umbrella term used to describe ongoing symptoms of COVID-19 for weeks, months or even years following the initial infection. It is often referred to as Post Covid Condition or Post Covid Syndrome by healthcare professionals.

Global prevalence estimates of Long Covid in children vary from 1:4 to 1:100 depending on cohort, methodology, and definition.

The latest data published by the Office of National Statistics estimated that 62,000 children in the UK are living with the effects of Long Covid, with 53,000 having symptoms for at least 1 year.

In a recent survey by Long Covid Kids, more than 50% of respondents reported children were still unwell and, or experiencing relapses up to 3 years post-infection.

\*\*\*

The symptoms of Long Covid in children can vary widely and can include:

- Extreme exhaustion or fatigue
- Post-Exertional Symptom Exacerbation (PESE).
  - a worsening of symptoms triggered by physical, cognitive, mental, social or emotional exertions, can happen immediately; or up to 24-72 hours after exertion. (To learn more about PESE please watch the LongCovid.physio video which is part of a series of videos they have produced)
- cognitive impairments (e.g. concentration, processing and memory)
- difficulties sleeping and unrefreshing sleep
- Headaches
- Gastrointestinal issues (e.g. cramps, diarrhoea, Gastric reflux, nausea and vomiting)
- Dizziness and visual disturbances
- Pain
- Long Covid can affect mental health and well-being.
  - The cause could be pathological, attributed to the long-term impact of living with the other symptoms, or as a direct response to health and education experiences. Symptoms can include: anxiety, depression and other emotional issues.

\*\*\*

### 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 have had Long Covid for almost two years. Due to Long Covid, my symptoms have changed widely and now in the present I've got quite a list. I've extreme fatigue at all time, and I'm constantly in pain. Loud noises or strong vibrations cause agony and I can spasm at any time. I can barely walk and have to use a wheelchair. The soles of my feet burn so much."

\*\*\*

The following is a non-exhaustive list containing commonly co-occurring diagnoses, syndromes, symptoms, and other terminology that you may hear in relation to Long Covid.

For brevity we have only included the main symptoms in this video, but a fuller list is provided in the handbook.

### Paediatric Inflammatory Multisystem Syndrome (PIMS-Ts), which can also be known as Multisystem Inflammatory Syndrome in Children (MIS-C)

This is an over-response by the body's immune system, triggered by Covid-19 infection, which leads to severe inflammation. It is an acute condition, which requires urgent treatment, often in intensive care (ICU). PIMS-TS occurs 2-6 weeks after a COVID-19 infection, in children with a genetic predisposition.

The Main Symptoms to be aware of are:

- Fever
- Rash
- Gastrointestinal issues

### Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS)

The Main Symptoms to be aware of are:

- Extreme Exhaustion/Profound fatigue & Post Exertional Malaise (PEM) /Post Exertional Symptom Exacerbation (PESE) – which is a worsening of symptoms after activity
- Muscle weakness, muscle and joint pain
- Flu-like symptoms such as sore throat and headaches
- Cognitive Dysfunction (eg. word finding difficulties, clarity of thought, memory problems)

Many of the symptoms of ME/CFS overlap with symptoms of Long Covid, however the relationship between the two conditions needs further research before conclusions can be reached.

Next we will look at PoTS.

### Postural Orthostatic Tachycardia Syndrome (PoTS)

The Main Symptoms to be aware of are:

- Fast heart rate (faster when standing or sitting upright than when laying down)
- Tight chest and palpitations
- Feeling dizzy and/or lightheaded when standing up

### Mast Cell Activation Syndrome (MCAS)

- There are a wide range of multiple symptoms across body systems (commonly including allergic symptoms such as hives, wheezing, and gastrointestinal issues). These symptoms can range in severity from unpleasant to debilitating, and can include the medical emergency anaphylaxis.

### Paediatric Acute-onset Neuropsychiatric Syndrome (PANS)

- For a patient to be diagnosed with PANS, they must have experienced an abrupt, acute onset (usually within 24 - 48 hours) of Obsessive Compulsive Disorder (OCD) or severely restricted food intake along with two or more other symptoms (e.g. tics and changes in behaviour). [Their experience should also not be better explained by another known neurologic or medical disorder.]

### Pacing

Pacing means that the focus needs to be on balancing activity with rest rather than pushing through exhaustion. Reviewing concepts such as pacing penguins, the energy envelope and spoon theory can help explain this in more detail.

### Crashes

This is the colloquial term that those with Long Covid may use to describe a period of worsening of symptoms and when their ability to perform daily activities is reduced. This could be a result of exertion, illness, hormonal changes and more. Crashes can be unpredictable and may link with PESE.

\*\*\*

### 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).

"When my son did any kind of activity he would then crash. It wouldn't necessarily happen straight away, or even the day after, but then he would sleep for up to 14 hours a day, for the next couple of days, but even so he would still feel tired after that."

\*\*\*

### Jake, 8, Long Covid with PANS

Video Transcript of Jake (Jake is a 8 year old white boy with an Irish accent. He has dark brown curly hair and is lying on the sofa. He is wearing an orange top and holding a mint green plush space dragon/cow).

"When I have a crash it's hard to sleep and it's like really hard to sleep, but, I also wake up in the night when I eventually get to sleep. And, all food is really disgusting and just like revolting and I don't really like it and it just makes me angrier, and I just get really angry and I throw pillows like off the couch."

### Invisible Illness

This is a term used when a child's condition may not appear immediately apparent to others, often because many of the symptoms are experienced internally.

### Masking

Masking can be either a conscious or unconscious change in behaviour and demeanour in order to appear well to other people. This is usually due to societal pressure and children often do this with people outside their home because they want to be seen as 'normal'.

The handbook that accompanies this series provides additional information.

\*\*\*

### Mother of two children 12 and 14, both with Long Covid

Video Transcript of a white woman with an Irish accent. She has dark brown wavy hair worn down and in this video she is wearing a black top.

"Two of my children got COVID in 2020 and have never recovered, they've missed almost 3, 4 years of school, have been unable to attend any of their activities, and are rarely well enough to meet up with friends. Some of their symptoms include: extreme exhaustion, severe debilitating daily headaches, daily high temperatures, abdominal pain and nausea, racing heart rate, low blood pressure, joint and muscle pain."

\*\*\*

Long Covid is a complex condition that can:

- fluctuate
- be episodic
- be relapsing and remitting
- affect any system within the body

New, prolonged or worsening symptoms require medical advice.

\*\*\*

Referral and diagnosis can be a protracted process; contributing factors can include:

- Clinical Awareness. This can vary between healthcare providers and some families report challenges in being believed or having symptoms taken seriously.
- Local Service Provision. Some services are set up for assessment or rehabilitation only and not all areas have an accessible Long Covid paediatric specialist service.
- Waiting Times. Our survey showed this was on average around 6 months, there are hopes that waiting times are beginning to decrease.

And finally,

- The family's ability to advocate for their child. This may be due to previous negative healthcare experiences or reduced health literacy as a result of poor public health messaging.

Whilst there is currently no cure for Long Covid it is possible to treat and manage a number of symptoms and for improvements in day to day function to be made over time.

Living with Long Covid can make school life more challenging, or even inaccessible.

Children who are too unwell to be in school can benefit from either temporary or permanent alternative provisions.

Children who are able to attend school may continue to need support arrangements such as a reduced timetable for a period of months or years.

It is good to remember that provision will need to be flexible and will require regular review.

\*\*\*

So as educators, what can be done to support children with Long Covid?

- Understand, recognise and increase awareness of Long Covid
- Signpost families and children to service provision & Long Covid Kids resources
- Liaise with healthcare professionals, including school nurses
- Provide flexible support

Lack of community testing can make it harder to link ongoing difficulties with a potential COVID infection.

Be aware of the wide range of symptoms, and watch for children who display signs that require further investigation.

Some children will not have the language to describe their experiences.

Children with Long Covid tell us they feel ill, sad, hurt, lonely, and dizzy and that they are in pain.

They describe it as draining, exhausting, tiring, scary, horrible and feeling like it is never-ending.

If you suspect a child may have Long Covid, speak to their parent or caregiver with them, and encourage the family to approach their GP.

\*\*\*

.

## 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)

"I have Long Covid and my main symptoms are fatigue, insomnia, PoTS, joint and muscle pain, tremors, and I have breathing issues. The fatigue, it's just utter exhaustion all the time. I'm waking up at midday, I'm getting up for maybe an hour, an hour and a half max and then I'm back to bed again for hours at a time. I have to plan weeks ahead on things I want to do such as going to the shops, and then I've got days in bed afterwards. The insomnia doesn't help 'cos because even if I'm utterly exhausted I just can't sleep. I'll get to sleep at maybe 2am after going to bed at 10. I'm exhausted all the time, I've had medications and everything, I'm just utterly exhausted.

The PoTS, I struggle walking around, I had to have bannisters added in because I was just falling into walls all the time, I was risking falling down the stairs, I would stumble backwards all the time.

The joint and muscle pains are ex... just debilitating, I can't do anything. I can't walk because my knee, ankle, hip pain is just so bad, I can't sit in chairs because I have got to have multiple pillows behind my back, 'cause otherwise my back will kill me.

I get tremors, which... my hands just shake constantly, I can't hold mugs still, I have to have a much less level of liquid in them just because ... dropping things."

\*\*\*

So, to summarise:

- Long Covid is an umbrella term to describe ongoing symptoms of COVID-19 for weeks, months or even years following the initial infection.
- The symptoms can vary widely and affect every system within the body.
- Symptoms can also fluctuate and be episodic, relapsing and remitting.
- Families report many challenges in accessing timely support and getting a diagnosis.
- Living with Long Covid can make attending school and accessing an education difficult too.

\*\*\*

We hope that this first video in the series has given you an awareness of Long Covid and highlighted some of the challenges children, young people and their families face in accessing healthcare and education support.

By providing early signposting with individual and flexible support strategies we can ensure that children are included, access their education, reach their educational potential and achieve the best possible recovery outcomes.

By listening, understanding and involving children, we can shape plans to support them and give them a greater sense of control, autonomy, confidence and empowerment.

\*\*\*

In the next video in this series, video 2, we discuss returning to school and the available Alternatives.

\*\*\*