VIDEO 5

DAY IN THE LIFE OF CHILDREN AND YOUNG PEOPLE LIVING WITH LONG COVID

L.C.K. Educational Toolkit.

Video 5 - Day in the Life of Children and Young People Living with Long Covid

Sometimes, when children and young people get sick from a virus, they get better quickly. But, for some, getting better can take a long time - and some may not fully recover.

When children have ongoing symptoms after a COVID-19 infection, this is called Long Covid.

It can make everyday things - like playing, learning, or even talking with friends - much harder.

Long Covid is an umbrella term which covers all the other names people use to describe the Ongoing Symptoms of COVID-19 - for weeks, months, or even years following the initial infection.

[Text only] The voices you will hear in this video are real children and young people living with Long Covid.

Marcie
Jay
Lilly
Evelyn

Marcie, 12 years old

Hi, my name is Marcie, I'm nearly 12 years old. I was diagnosed with Long Covid last
year but, I've been having symptoms since 2021.

My main symptoms are feeling weak and dizzy, which doesn't give me enough energy, and makes it hard to concentrate on things, and I get brain fog most of the time.

[Text only] Brain Fog? It's a cognitive dysfunction which includes… trouble with memory, difficulty concentrating, getting easily overwhelmed with information.

I also have headaches, tummy aches, and aches and pains.

[Text only] Mornings. Getting Dressed is Really Tiring.

When I get up for school I have enough energy but, by the time I get there I'm usually quite exhausted.

I normally feel quite tired after one or two lessons. I find it hard to concentrate on the third lesson sometimes, on bad days, because of brain fog.

[Text only] Chart - Hours Spent at School which shows a typical school day at 7 hours and Marcie's at 3. 'I can't manage a full day.'

I usually go home before lunch. If I am at school I stay in for lunch and break time in a quiet classroom [Text only - Too Noisy!!!] with one of my friends [Text only - Much Better!!]

[Text only] Listening, thinking and watching is tiring.

After school I am really tired as I have spent all of my energy at school, even if I am tired, sometimes I can't get to sleep at night [Text only - my brain is too busy, my legs hurt, I'm so tired, I can't sleep].

Since having Long Covid I haven't been able to do as much physical activity as I used to, meaning that I don't do PE at school. If I do too much activity then I have a crash in the next few days of the week, and all my symptoms flare up [Text only - headaches, tummy aches, aches and pains].

<u>Long Covid Symptoms</u>

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

- Extreme Exhaustion or Fatigue
- Post Exertional Symptom Exacerbation - A worsening of symptoms triggered by physical, cognitive, mental, social, or emotional exertions. Can happen immediately, or up to 24 to 72 hours after exertion.

Jay, 13 years old

My name is Jay, I'm 13 and I've had Long Covid for just over 2 years.

I have difficulty walking and standing, and I can't stand up for very long. I have fatigue, (um) which makes me sleep for very long and I'm always tired.

(Um) I have peeling fingers [Text only - ouch], (um) brain fog, so it's hard for me to listen and to follow conversations, and I have to try and break down conversations to understand them.

The private Long Covid Clinic really helped me, because they listened really well and they understood all of my symptoms. I wanted to start these tablets because I wasn't able to walk for a year, and I wanted to try and stand and walk again.

[Text only] Chart - zero hours at school

I haven't been able to go to school in a year, and my mom used to homeschool me, but I couldn't focus for more than 10 to 20 minutes. (Um) I now have a tutor who tutors me (um) for, for 3 days a week, for 30 minutes. [Text only - I miss my friends].

Text only] I sleep all morning until lunchtime. 'Time to wake up Jay!

My mom usually wakes me up at (um) lunchtime, and she usually gives me something to eat, and my tablets. So, I take my tablets, and I might eat something, but I might not. (Um) I usually eat maybe fruit, and I come downstairs and I lie on the sofa. And then, to get around I usually crawl around, or I use my Walker, but I can't do more than two to three steps, and I usually sit on it to get around.

[Text only] DRs and scientists are still learning about Long Covid.

It's hard to find doctors that can help with Long Covid and help with my symptoms. Also I don't think (uh) some of my family and friends understand what Long Covid is, and how it affects me, and how long I sleep for, and the brain fog.

[Text only] 'Why is he sleeping so much?' 'Can I catch Covid from him?' 'No, he's not infectious any more.'

[Text only] - ‘how much energy I have’ - counter goes up to 50%, ‘Visit Doctors’ - counter goes down to 30%, ‘See friends’ - counter goes down to 0%.
And I have to save my energy for going out to appointments, and (um) when a friend comes over, so (um) after I have crashes.

I worry about how long it's going to take to get back to my old life, (um) ‘cause I want to play football, and boxing, and go to school like a normal person.

[Text only] Children with Long Covid all have a unique set of symptoms that may differ in severity.

[Text only] Some More Long Covid Symptoms

- Cognitive Impairments, for example: concentration, processing, and memory.
- Difficulty sleeping and unrefreshing sleep.
- Headaches.
- Gastrointestinal issues, for example: cramps, diarrhea, gastric reflux, nausea and vomiting.
- Dizziness and visual disturbances.
- Pain.

Lilly, 16 years old

Hi, I'm Lilly. I'm 16 years old, and I've had Long Covid since a month after I turned 13. [Text only - ‘I’ve had Long Covid for over 3 years!]. My main symptoms are chronic fatigue, brain fog and chronic pain.

Many aspects of my Long Covid aren't visible on my body, though I'm almost completely covered in a blotchy skin condition. Most of my symptoms also could not be explained by medical professionals. With my debilitating chest pain sending me into A&E more than once, requiring several ECGs, and chest X-rays, and a heart ultrasound, before finally being declared as - nothing obvious.

I find walking and standing particularly difficult. I walk with a cane and use mobility scooters or wheelchairs where I can.

I stopped going to mainstream school in May 2021, after several months of a restricted school timetable. I do online tuition from home, and have done since the end of year eight. I've had a maximum of seven hours of lessons a week, and a minimum of two or three. At the moment we are settled on five hours.

Life has changed dramatically for me since I contracted Long Covid. I can't go out by myself like many other teenagers, as I could have a medical emergency, and this means I can't join in with typical experiences with my friends.

What is Postural Orthostatic Tachycardia Syndrome?

Next, let's look at PoTS - Postural Orthostatic Tachycardia Syndrome. 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.

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 behavior and demeanor 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'.

Ambulatory Wheelchair Users

Ambulatory wheelchair users can stand or walk, but their ability to do so varies due to things like energy levels and pain. So they may use a wheelchair to manage this.

They may sometimes use a different mobility aid such as a stick or crutches, or on good days, may not need any aid at all.

Evelyn, has had Long Covid for two years

[Text only] Does anything help?

I don't think that there's any specific thing that helps me. I mean mainly it's just rest, rest all the time, even if you don't want to. [Text only 'It's very boring]. And, no matter how much you rest, you aren't really going to feel anything different. You know it's helping you, but sometimes it can be really frustrating 'cause it feels like it doesn't.

Studies are hard. I've always liked doing studies, whether I was good at it or not. But, now they're just plain hard. When I try to do math, it all jumbles up in my head, and it's just kind of hard to understand. It's kind of discouraging sometimes, (um) because I used to be good at stuff and now, when I look at this stuff, it just doesn't work out for me.

[Said tearfully] I worry about time. Time is a tricky thing. It kind of just keeps going, and you can't stop it. And so, I worry that I won't be able to complete all of the things that I want to do. I worry that the time for doing many things, as a child, is passing. I worry that, I worry that I'm disappointing myself. I know it sounds silly, but it's hard - not knowing how long this thing will last - it's probably the hardest part. If I could just have a deadline - even if it was for four or five years - knowing that it would be over by then, would be so much better. It's the uncertainty. Us humans don't like uncertainty, because it's hard to grasp. And so I worry about that - not knowing when it will end - and not knowing if I'll be able to complete everything I want to.

Everyone's experience of Long Covid is different, but one thing is always true - knowledge, kindness and understanding can make a big difference.

If you or someone you know is living with Long Covid, remember that you're not alone. There is support and help available.

To learn more visit - LongCovidKids.org. You'll find information, resources, and ways to connect with others who understand.

[Text only] Together, we can support each other.

Video 5 Run time (12 minutes 52 seconds)