

# Long Covid in Children and Young People

This leaflet is based upon our research into Long Covid in children and young people.

Our research interviewed children, young people, and their families to hear their experiences of life with Long Covid.

More information can be found on the SPLaT-19 website (https://www.keele.ac.uk/ctu/researchportfolio/activeresearch/splat/).

This leaflet has been produced with children and young people with and without Long Covid, to be interesting and engaging to younger audiences.

We would like to thank everyone who has been involved for their work on this project.

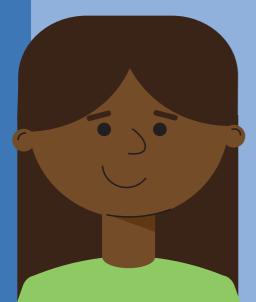


#### What is Long Covid?

COVID-19 is the infection caused by a virus called SARS-COV-2. Most people who have COVID-19 recover quickly but some people have symptoms which last a long time.

Long Covid is the name for symptoms which last longer than four weeks after COVID-19 and which aren't because of another illness; some people also get new health problems after having COVID-19.

Long Covid affects people of all ages - children, young people and adults – and can happen to people who had severe or mild illness with COVID-19.



Long Covid affects everyone differently.

Someone with Long Covid may find it difficult to do certain things. This might include:

- going to school or work,
- doing daily tasks,
- concentrating,
- having control over their emotions,
- having conversations.



# How do people get Long Covid?

Long Covid isn't contagious. You cannot catch Long Covid from anyone, even if they have symptoms of Long Covid.

## How long do people have Long Covid for?

People with Long Covid take different amounts of time to get better. For some people it can take weeks or many months to feel well again.

The length of time that people have Long Covid doesn't always link to how ill they felt when they had COVID-19.

Recovery from Long Covid isn't a straight line, and it is normal for symptoms to sometimes feel worse and then sometimes feel better. This will depend on the person. Everyone's experience is different.



# What are the different names that people use to describe Long Covid?

Long Covid is a name that was first thought of by people who wanted to describe the symptoms they had and talk about their experiences.

Other words that people may use when talking about Long Covid are:

- Ongoing symptomatic COVID: where covid symptoms last between 4 and 12 weeks after people first feel ill
- Post-COVID syndrome: when someone has covid symptoms which last over 12 weeks after they first felt ill
- The World Health Organisation uses the name 'post COVID-19 condition'.
- Other people have used terms like 'post covid', 'long haul covid'.

Most healthcare professionals will understand the term Long Covid, even if they use a different word.



## How does Long Covid affect children?

Many children and young people experience effects of COVID-19 that last longer than four weeks. Symptoms vary and can be mild, moderate or severe.

Everyone experiences Long Covid differently. Research has found that around 15 out of every 100 children or young people who get COVID-19 will have Long Covid, this is like 2 or 3 people in a class at school.

Children and young people won't all share the same symptoms, and those that do have similar symptoms (for example, feeling fatigued) may not experience these in the same way.

Symptoms may get worse after doing exercise and may improve after rest.

These symptoms might not always be visible to other people. Some people with Long Covid can look well but feel unwell.

They may be unable to take part in activities or might need help with things that they used to be able to do by themselves.

#### The most common symptoms are:



Fatigue – this is a severe exhaustion, and not the same as being tired after a busy day. People with fatigue may feel like there is no more energy in their battery.

Fatigue



Difficulties thinking, "cognitive dysfunction"– finding it difficult to focus, experiencing brain fog, and other problems with thinking, memory or concentration. This can make talking, reading and writing difficult.

Cognitive Dysfunction

Smell

Smell/taste problems – some people find that foods they used to enjoy taste different or have found that they are unable to smell things anymore. This can also change people's appetite and eating habits

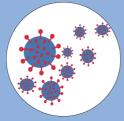
Taste



Headache



Shortness of Breath



Cough



Chest Pains



Muscle Aches/Pains



Difficulty Sleeping



**Fever** 

Anxiety or a Low Mood



# What to expect if you go to the doctor about symptoms which might be Long Covid

If you are unwell, you can go and see you GP for help.

The GP will listen to your story, ask you about your symptoms, when they are worse and when they are better, and how they affect your life.

They may wish to examine you, for example check your pulse rate, and listen to your heart and breathing. The GP may request some blood tests, depending on your symptoms.

> It is likely that you will be advised to try simple measures, for example, taking gentle exercise, advice to improve sleeping well, and talking to school.

> If you have tried these things and are still having difficulties, then you may be referred to a specialist clinic at a hospital where the team will talk to you and your family.



## What it is like to experience Long Covid?

Symptoms of Long Covid can prevent children and young people from doing activities that they used to do, like spending time with friends or going to school. It might be that they need some things to be adapted so that they can take part. This will depend on the person.

Here are some quotes from the children and young people involved in our research:

"It was like every single day I just need to rest, that was it, I just like let myself actually rest and not really do anything except for like get up in the morning, brush my teeth, have a bath. That was it"

Sam, Aged 17

Some people who have recovered from Long Covid are very nervous about getting COVID-19 again.

They said that sometimes this can make them nervous around people with a cough or cold, and said that sometimes they have asked if people have tested themselves for COVID-19, because they do not want to develop Long Covid again.



#### How Long Covid can affect hobbies

Some young people with Long Covid weren't able to do their normal hobbies or had to change what they normally did, particularly for active hobbies like sports, gymnastics or dance.

For some young people, this led to them developing new hobbies which they could do even when their symptoms stopped them from doing other activities.

> "Yeah we used to go on a lot of walks and I used to do a lot of running at school with my friends but I don't do that that much anymore because it's really tiring"

> > Morgan, Aged 12

#### How Long Covid can affect friends

Symptoms like fatigue and brain fog mean that it can be difficult for young people with Long Covid to visit or hang out with friends. While some people have moved to talking with their friends online, others haven't been able to keep all of their friendships and described being socially cut off

> "I just used to hang out with my mates all the time, but then obviously I couldn't... they were all hanging out and I wasn't in so it was kind of rubbish"

> > Frankie, Aged 17

#### How Long Covid can affect family

Symptoms of Long Covid, like fatigue, meant that children and young people with Long Covid couldn't take part with family activities. Sometimes, activities had to be cancelled for the whole family because they couldn't take part.

"it's very difficult to plan days out. Like we used to do, like obviously normally days out over the holidays and things and go places. Which we haven't really been able to do, it sort of basically has to be spur of the moment stuff. If she wakes up in the morning, she's having a good day, it's like oh yeah shall we try and go here, shall we try and go there."

Parent

#### How Long Covid can affect school life

Symptoms like brain fog and fatigue or sensitivity to lights or sounds, made it difficult for people with Long Covid to concentrate in class.

Some children and young people have had to have time out of school or attend on a reduced timetable to help them rest because of their symptoms, or to take time out to go and see healthcare professionals.

Children and young people with Long Covid described how this meant that they fell behind with work or dropped grades, weren't able to keep in touch with their friends which had a wider impact on their friendships and education.



National Institute for Health and Care Research







#### **Helpful Resources**

# For more information on Long Covid visit these helpful resources.



- https://www.yourcovidrecovery.nhs.uk/childrenand-young-people-with-covid/
- https://www.sign.ac.uk/media/1825/sign-longcovid-patient-booklet-v2.pdf
- https://healthtalk.org/Family-experiences-of-Long-Covid/overview
- https://epicfriends.co.uk/
- https://www.nhs.uk/conditions/COVID-19/longterm-effects-of-COVID-19-long-covid/

This project (grant reference 686) is funded by the National Institute for Health and Care Research (NIHR).

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

