

LONG
COVID
KIDS

Shining a light on Long Covid in
Children & Young People
Recognition. Support. Recovery.



Long Covid Kids believe all children should be able to thrive and look forward to a positive future.

That is why we represent and support children and young people living with Long Covid and related illnesses and the parents and caregivers that look after them.

Our mission is fourfold:

Awareness

To raise awareness of the symptoms of Long Covid and related illnesses in children and young people, to increase understanding, aid early diagnosis and improve response and intervention.

Support

To connect and support children and young people living with Long Covid and the parents and caregivers that look after them.

Research

To fund and participate in global research to investigate health implications, improve the lived experience and enable recovery.

Action

To represent the interests of children and young people living with Long Covid in expert forums, research panels, health organisations and parliamentary groups. To campaign to mitigate the risk of SARS_CoV_2 infection in schools and place wellbeing at the heart of education.



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Founder & CEO



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Founding Member
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Data Analyst Consultant

Welcome to the Long Covid Kids Support Pack

When my daughter and I developed ongoing symptoms after SARS-CoV-2 infection in early 2020, the term 'Long Covid' didn't even exist. The expectation was that people would recover in two weeks. Unfortunately, for many people, this is not the case.

Doctors, scientists and people with lived experience have learnt a lot in two years; this pack aims to share that knowledge and improve the outcome for families, children and young people living with Long Covid.

In keeping with the ever-changing research landscape, this digital guide is a practical and current 'living document' collated for children and young people living with Long Covid and the families and professionals who support them. The guide will continue to evolve alongside the global efforts of researchers and clinicians, who are working so hard to unpick this new condition, and the unwavering support of our Long Covid Kids champions.

Long Covid Kids have been connecting and supporting families, children and young people living with Long Covid since October 2020. To find out more about our support services please visit us online at www.longcovidkids.org

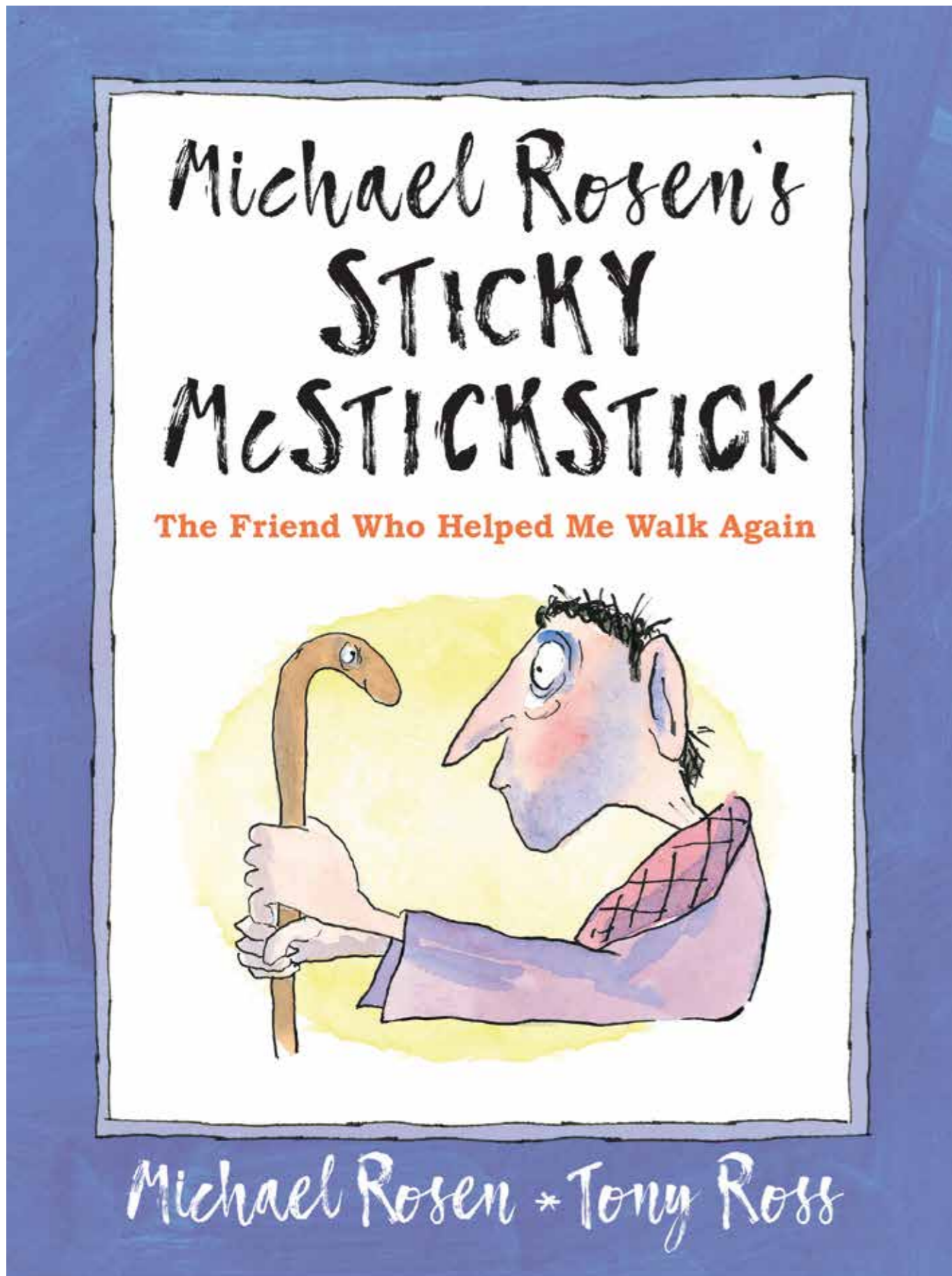
We hope our collective knowledge helps you to navigate this novel condition and offers renewed reassurance that you are not alone although there are challenges to overcome.

Made by families living with Long Covid, with love.

With a special thank you to our LCK Champions
www.longcovidkids.org/champions

Long Covid Kids Support Pack is supported and endorsed by:





Cover illustration from MICHAEL ROSEN'S STICKY MCSTICKSTICK: The Friend Who Helped Me Walk Again
Written by Michael Rosen; illustrations © 2021 Tony Ross
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www.walker.co.uk



Michael Rosen
Patron

Michael Rosen is one of Britain's best loved writers and performance poets for children and adults and has personally been affected by Long Covid. He is currently Professor of Children's Literature at Goldsmiths University, London and has taught on MA courses in universities since 1994. He was the Children's Laureate from 2007-2009 and has published over 200 books for children and adults.



Book trailer for Sticky McStickstick by Michael Rosen, illustrated by Tony Ross

www.youtube.com/watch?v=q2v6da_z5yk

A message from Michael Rosen

Long Covid exists. Some people are lucky: they got Covid or they will get Covid and there are no long-term effects. For others, it can be mild, quite serious or very serious. It can be not very long, quite long, very long or forever. I'm someone who has two effects which are forever: I've lost most of the sight in my left eye and most of the hearing in my left ear. These were a result of having 'micro bleeds' (haemorrhages) in my brain which seem to have knocked out part of the nerves that go into the eye and ear.

One way to talk about this is to say that my life has changed. Sometimes it's that I'm a bit clumsy because I misjudge where the edge of the table is, or that I miss the cup where I'm pouring some milk. Sometimes it's that I find restaurants and parties quite difficult. I wear a hearing-aid to give me wrap-round sound but it can make the sound of the gathering like a roar. If I take the hearing-aid off, I can only hear the person on my right-hand side.

Why am I telling you this? Not because I'm the only person who came out of Covid with long-term or life-time symptoms. Far from it. There are thousands of us and our lives have changed. Some people need a lot of help – physical and mental. We also need to have a conversation about how to take this matter seriously. This Support Pack does just that. It takes the whole thing very seriously indeed and more: it helps.

I'm delighted to endorse it.

LCK Support Services



LCK Support Services
bit.ly/3ubnDd3
LCK Safeguarding
bit.ly/3L4w4h7
LCK Chatbox
bit.ly/3LO8DFG
LCK Connected
bit.ly/3qo7AHC



Sign up to Padlet here
bit.ly/3CZDgZ7
For children and young people
bit.ly/3ugaDCT
[not working?]
For parents and families
bit.ly/3qqa7Bg
[not working?]

You are not alone.

Families using our Support Services have reported that connecting with other families sharing a similar experience to them has been “a lifeline”. We recognise the challenges that families are facing. Our team are living them too.

Like you we continue to show up each day for our children – searching for answers, connecting the dots, caring, supporting. Protecting. In March 2022 there were over 10,000 members engaging with Long Covid Kids Support Services. Membership grows by 150 to 200 a week. We began as a grassroots international Facebook group and now have our website, social media accounts and Support Services.

Since becoming a UK based international charity in October 2021 we have been able to evolve and extend our services to meet the growing needs of parents, children and young people. At the beginning of 2022, we proudly launched two new free members services for families and children. To help us adhere to our safeguarding policy our Support Services require pre-registration.

ChatBox online forum

ChatBox is a space for parents, caregivers, children and teenagers from ages 8-17 years to communicate online. Separate age-appropriate channels provide a safe space for peer-to-peer support:

- Age 8-11 years
- Age 12-14 years
- Age 15+ years
- Parents & caregivers

Members can choose to be part of specific topics and discussions that interest them. For example, children can connect with other children, form supportive friendships in their country, with similar interests, with children of similar ages or with a comparable duration of symptoms. ChatBox can be used in between LCK Connected sessions to continue to build relationships and gain support.

LCK Connected

LCK Connected offers weekly Zoom HangOuts led by our experienced volunteer team and provides a welcoming session for children from ages 6-17 years, parents and caregivers. Members can actively participate and chat with cameras on, others pop in to say ‘Hello’ at the start and then switch their camera off, hang out, chill and listen. Members often choose to continue discussions, friendships and peer to peer support via ChatBox

Padlet

Padlet is an interactive website/app that provides a visual library of internet links that our team will update as new information emerges. Think of it like a scrapbook of useful links. Since the start of the pandemic, Long Covid Kids have been collating resources and information to help us improve recognition, support and recovery.

We have five Padlets for different audiences;

- Children
- Young people
- Families
- Schools/education professionals
- Health and social care professionals

Sign up with the links at the top of the page.

Download key

- Link to website
- PDF download
- Link to YouTube

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Glossary & abbreviations

General terms

Children: Encompasses children, teenagers and young people (aged 0-17).

COVID-19: The name for the disease/infection caused by the SARS-COV-2 Virus.

CYP: Child(ren) and young person/people

Parent: Encompasses parent/guardian/caregiver/person with parental responsibility.

LCK: Abbreviation for Long Covid Kids charity.

Long Covid: Patient defined umbrella term that refers to anyone who has ongoing symptoms for four or more weeks post acute COVID-19 infection. Also known as Post Covid Syndrome or Post Acute Covid Syndrome.

Long Covid has been referred to as an **Episodic, Fluctuating, Recurring, or Relapsing and Remitting** health condition. This means it is characterised by health-related challenges (or disability) that may be multidimensional, episodic and unpredictable in nature.

Team: Anyone involved in a child's care including parents, school, health and social care staff, as well as advocates and certain voluntary organisations.

Health and wellbeing terms

ACT: Acceptance and Commitment Therapy.

Antigen: An antigen is a substance that causes our immune systems to produce antibodies. Therefore antigen tests are designed to detect the presence of this substance.

Asymptomatic: This refers to someone who has the virus who is not displaying obvious symptoms of it.

Autoimmunity: This is the presence of antibodies that are directed at a person's body rather than antibodies directed against an external invader, such as a virus or bacteria. Most people have some autoimmunity that is managed by other systems in the body but in some cases the antibodies start attacking healthy cells or tissue and can cause autoimmune diseases.

Autonomic: Refers to the functions of the part of your nervous system that controls involuntary actions, such as your heart beating.

Biomarker: A body characteristic that can be measured eg blood pressure, and used as an indicator of normal or pathological processes **or to an exposure.**

CAMHS: Child and Adolescent Mental Health Service.

CBT: Cognitive Behavioural Therapy.

Coronavirus: Coronaviruses are one type of virus. There is more than one Coronavirus. The one that causes the disease COVID-19 was called SARS-CoV-2.

CPET: Cardio-Pulmonary Exercise Test.

Endemic: Referring to the usual prevalence of a given disease or infection in an area or group. Endemic conditions do not exhibit wide fluctuations over time in a defined place.

EWMHS: Emotional Wellbeing and Mental Health Service.

GAS: Goal Achievement Scale (a system used to set goals).

GP: General Practitioner.

IST: Inappropriate Sinus Tachycardia (a medical condition where a person's heart rate speeds up when it is not usual to do so).

LFT: Lateral Flow Test – these are the rapid tests usually performed at home and that were initially developed to pick up asymptomatic cases.

Long Covid Hub: An assessment centre that brings together experts on common symptoms such as respiratory problems and fatigue who can treat youngsters aged up to 18, advise family doctors or others caring for the children or refer them into specialist services and clinics.

Longitudinal: Repeated observations of the same variables (e.g. people) over time.

MCAS: Mast Cell Activation Syndrome.

ME/CFS: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

MIS-C: Multisystem Inflammatory Syndrome in Children – the name used in the US and internationally for what the UK calls PIMS-TS.

Mutation: All viruses mutate. As they try and replicate in a host they don't always make an exact copy. Most mutations are harmless but some change the virus in a way that makes it better able to invade our immune systems or avoid vaccines or treatments. This is a risk while the virus is circulating in a population. Potential consequences of new variants include: change in transmissibility, difference in disease severity, ability to evade detection by viral diagnostic tests, reduced

susceptibility to treatments, ability to evade natural or vaccine-induced immunity.

NHS: National Health Service (in the UK). This is a service designed to be free at the point of need.

NICE: National Institute or Clinical Excellence in Health (sets evidence based guidance for health in the UK).

Novel: COVID-19 is referred to as a 'novel' virus, in that it had not previously been detected in humans. This means that it is likely that there is no previous immunity in a population making everyone susceptible to the effects of the virus.

Occupations: The activities we take part in every day. These are often categorised into self-care, work/school and leisure.

OT: Occupational Therapist.

PANS: Paediatric Acute-onset Neuropsychiatric Syndrome.

PASC: Post Acute Sequelae of COVID-19 – used to describe long lasting COVID-19 symptoms in the US.

PCC: Post COVID-19 Condition – used by the World Health Organisation to describe long lasting COVID-19 symptoms in adults.

PCR: Polymerase Chain Reaction – A PCR test is the test that is sent away to a laboratory to analyse.

PCS: Post COVID-19 Syndrome – the term for long-lasting symptoms of COVID-19 infection used by The National Institute of Clinical Excellence in Health.

PEM: Post Exertional Malaise.

PESE: Post Exertional Symptom Exacerbation. bit.ly/352ldVw

PIMS-TS: Paediatric Inflammatory Multisystem Syndrome temporally associated with Severe Acute Respiratory Syndrome Coronavirus 2.

POTS: Postural Orthostatic Tachycardia Syndrome.

PT: Physiotherapist.

Receptor: A cell or group of cells (or part of a cell) that receives and binds to specific stimuli.

Rhinovirus: Infections that cause the common cold.

SALT: Speech and Language Therapist.

SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus 2.

SMART: Specific, Measurable, Occupation

–centred, Relevant, Time-orientated. A system used to set goals

SPECT-CT SPECT is short for single-photon emission computed tomography. This scan is a type of nuclear medicine scan where the images or pictures from two different types of scans are combined together. The combined scan can provide precise information about how different parts of the body are working and clearly identify problems.

Strain: When a different variant of a virus becomes established in a population.

Tachycardia: Fast heart rate

Variant: This happens when a virus doesn't produce an exact copy of itself (mutation) and over time the virus changes its genetic make-up to create a new variant.

Virus invasion: This is where a virus enters a host (such as an animal and human) and invades the cells of that host. It does this to survive and it survives by replicating itself.

WHO: World Health Organisation.

Education terms

EHCP: Education Health and

Care Plan.
ELSA: Emotional Literacy Support Assistant.

EMHP: Education Mental Health Practitioner.

EP: Educational Psychologist.

IHP: Individual Health Plan.

LA: Local Authority (i.e. your local council).

QFT: Quality First Teaching.

SEN/SEND: Special Educational Needs/and Disabilities.

SENCo/SENDco: Special Educational Needs/and Disabilities Coordinator

SENDIASS: Special Educational Needs and Disability Information, Advice and Support Service.



Section 01

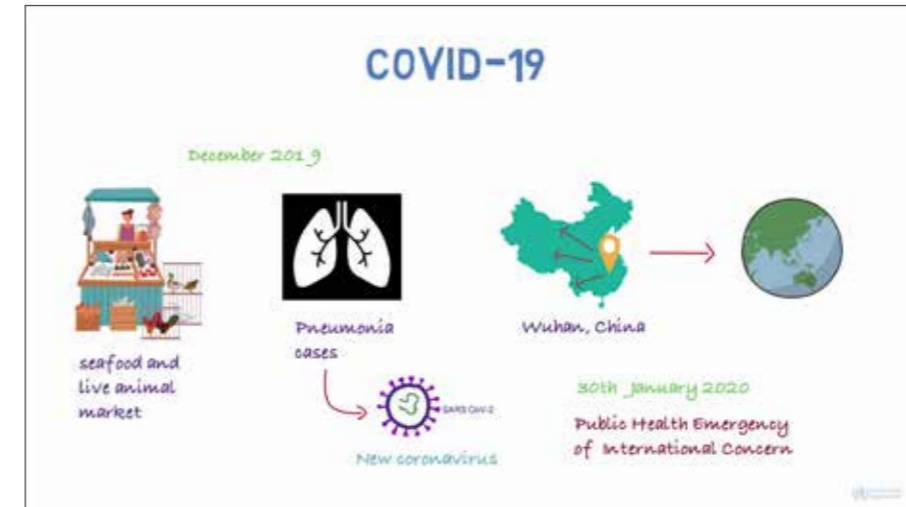
ABOUT COVID





What is COVID-19?

In 2019 a novel virus named SARS-CoV-2 was detected in China. COVID-19 is the name of the disease caused by the SARS-CoV-2 virus. COVID-19 is new and unique with mutations and variants arising over time. Clinical scientists, researchers and patients are therefore learning about it at the same time as it is evolving.



Click on each of the images left to watch two short videos from the World Health Organisation (WHO) on the origins of COVID-19 and how the virus transmits.



Five ways that SARS-CoV-2 is different to flu

With thanks to Dr Stephen Griffen
Associate Professor of Viral Oncology

SARS-Cov-2 is often compared to the common cold or seasonal flu. This is because initial symptoms can be similar.

Did you know that initial cold and flu-like symptoms are commonly experienced after infection from many viruses?

01

SARS-CoV-2 affects the whole body, not just the lungs and upper respiratory tract

Many other viruses can do this too. However, the frequency at which this is occurring is far higher in COVID-19 than in other viral diseases. Why?

- We tend to vaccinate against concerning viruses in childhood.
- Most other concerning viruses are at predictably low numbers/mitigated by vaccines.
- Unlike flu, SARS-CoV-2 is not seasonal.

Organs can be affected by COVID-19 even without the host realising it. For example, research shows that young, fit people who have had mild or even asymptomatic infection can develop myocarditis. The USA now recommends a medical assessment prior to returning to physical activity and sport.



<https://bit.ly/3D142jO>

02

SARS-CoV-2 causes loss of taste and smell

Flu has many symptoms in common with coronaviruses, such as a headache, sore throat, fever, cough, and shortness of breath. It's not easy to tell the difference without a test. However, it is unusual for the flu to cause a loss or change to your senses of taste and smell.

03

SARS-CoV-2 is more contagious than flu

SARS-CoV-2 is more contagious than flu and as the virus has evolved it has become more contagious still. Non pharmaceutical interventions (NPIs) such as masks and distancing that, to a large extent, held SARS-CoV-2 in check, effectively eliminated flu.

A person infected with SARS-CoV-2 can also be contagious for a longer period of time. It is also possible to be reinfected with SARS-CoV-2 and experience Long Covid again after apparent recovery.

04

SARS-CoV-2 triggers additional conditions

SARS-CoV-2 can cause different complications from flu in healthy children as well as those with common underlying conditions such as asthma.

These complications include blood clots and pediatric multisystem inflammatory syndrome temporally associated with SARS-CoV-2 (PIMS-TS).

There is also emerging evidence of long-term risk of other diseases following SARS-CoV-2 infection, notably early evidence of diabetes.

It is only with time and scientific investigation that we will know more. Sadly an average of 18 children die per year in England due to flu. Since 2020, 145 children have died due to COVID-19.

05

SARS-CoV-2 risks long-term illness

Many viruses have been associated with complications occurring sometimes decades after the initial infection, including cancers, inflammatory and auto-immune conditions. We have recently learned that the Epstein Barr virus is thought to cause a considerable proportion of multiple sclerosis. Polio causes post polio syndrome. We see signs that SARS-CoV-2 is causing long-term illnesses in a similar way including neuro-cognitive dysfunction. And then there is Long Covid.

We don't know how each child will respond to SARS-CoV-2 infection or new variants. As yet we don't know how each child suffering long-term illness after SARS-CoV-2 infection will recover. Nor do we know why.

What is Long Covid?

Long Covid is the term given to the ongoing signs and symptoms caused by SARS-CoV-2 infection. It is generally used to indicate symptoms and clinical signs that remain unresolved for four weeks or longer. Symptoms of Long Covid can also appear some time after an asymptomatic infection.

Long Covid was coined by patients who challenged the early COVID-19 guidelines that stated people recovered from mild cases within two weeks. It is called other terms around the world such as Post-COVID-19, Post Covid Condition and Post-Acute Sequelae of COVID-19 (PASC).

Long Covid was first recognised by patients at the beginning of the pandemic when they noticed that symptoms such as those of pneumonia, chilblain like sores and many others were not resolving with time.



bit.ly/3qpiwVy

Research conducted by both patients and clinical scientists

has since proven that the prolonged signs and symptoms of SARS-CoV-2 infection can include damage and dysfunction to all body systems and organs. Symptoms range from chronic loss of smell and fluctuating rashes to neurological and neuropsychiatric symptoms. Some children living with Long Covid have also eventually received a new diagnosis of conditions such as Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS), narcolepsy and organ damage.

There is no specific test or biomarker for Long Covid and diagnosis is generally by exclusion of other illnesses and syndromes. Some specific tests like a SPECT scan, however, can reveal Covid-related damage, such as damage to the small vessels in the lung. Many people living with the disease were previously fit and healthy. Scientists are currently working hard to discover biomarkers for Long Covid and there are a number of promising studies nearing completion.

NICE produced a rapid guideline on the management



Long COVID Physio
What is Long Covid?
bit.ly/3lz5xGY



NICE, together with the Scottish Intercollegiate Guidelines Network (SIGN) and Royal College of General Practitioners has published a book that explains Long Covid in more detail. bit.ly/3qpl9pm

WHO definition for Long Covid in adults
bit.ly/36EgfyC

of Long Covid in November 2021. They described Long Covid as the presence of signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for 12 weeks or more and are not explained by an alternative diagnosis. This includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and long term consequences of COVID-19 (12-weeks or more). Long Covid Kids is referenced as a resource in this document.

Understanding Long Covid

The National Institute for Health Research (NIHR) second themed review on Long Covid stated there may be grounds to understand Long Covid as up to four syndromes with different underlying causes and treatment needs.



www.nihr.ac.uk/news/nihr-publishes-second-themed-review-on-long-covid/27232

These could include:

- Long-term organ damage
- Post Viral Syndrome

- Post Intensive Care Unit (ICU) Syndrome
- Potentially an entirely novel syndrome separate from the others that could more specifically and uniquely be identified as 'Long Covid'.

It is important to note that these long-term effects on health may coexist in the same person.

A note on Post ICU syndrome

Post ICU syndrome is a well known phenomenon in medicine and points to the long-term impact of the intensive care experience on a patient. Doctors and researchers must distinguish the effects of Post ICU syndrome from the damage caused directly by Covid. They both can persist even after hospital discharge. Most children do not need ICU treatment for Covid and related conditions, but this might happen in some cases, for example, with PIMS/MIS-C.

These syndromes are consistent with the experiences shared in the Long Covid Kids Peer-to-Peer Support Group.

With thanks to Dr Elisa Perego
MAPHD

It's going to take years to understand the full impact of SARS-CoV-2 but there are many studies underway seeking to understand and track Long Covid in the UK and globally. Long Covid Kids are proud to be involved in coproducing research and representing lived experiences.

Long Covid Kids and others who are speaking up for children are also working hard to ensure transparency of data. As it stands the prevalence of Long Covid is not counted in UK statistics nor do we know the outcome of the child Covid-19 hospital admissions each month. Long-term friend to Long Covid Kids, **Dr Elaine Maxwell**, has recently called for a National Sentinel Audit of Long Covid to obtain standardised data.



www.england.nhs.uk/author/dr-elaine-maxwell/

We do however, have the benefit of our world renowned Office for National Statistics estimates and hope that this vital reporting service will continue.

What are the mechanisms that lead to Long Covid?

With thanks to
Professor Danny Altmann
& Dr Stephen Griffen

Emerging research is helping us to understand the causes of Long Covid. Whilst we haven't got all the answers yet, current available research points to some of the following:

01

Autoimmunity

Infection triggers autoimmunity as seen for example in Lupus. Here, the induction of autoimmune antibodies to different proteins in the body would be compatible with many of the diverse symptoms described, from microclots to endotheliitis and brain fog.

02

Endotheliitis

This is where the lining of blood vessels becomes inflamed due to abnormal presence of white blood cells in the vessel lining. This in turn prevents oxygen getting into the tissues. The overall effect is to cause various problems with the end organ including heart, lung, kidney and brain.

03

Abnormal microclots

This is where little clots form in the very small blood vessels supplying the end organ such as heart, lung, kidney and brain. This means that blood is unable to deliver oxygen to the tissues efficiently, leading to worsening function in the end organ.

04

Platelet activation

This is a series of responses which allow platelets to react after an injury. Due to abnormal platelet activation SARS-CoV-2 infection can cause problems with the blood flow in small vessels.

05

The virus remains within the body.

The virus persists in certain areas of the body such as the gut, brain and gonads long after a person becomes infected – this can potentially cause chronic, immune stimulation.

06

Brain effects

Brain effects might be due to SARS-CoV-2 infecting cells within the brain that help support the nerve cells, which can both cause direct damage, as well as triggering inflammatory responses that can interfere with neural function.

07

Dysregulated immunity

The idea that, as in glandular fever, the presence of virus disturbs the regulation of normal immune function.



For more up-to-date information, download the following:
Early clues regarding the pathogenesis of long-COVID - ScienceDirect
bit.ly/3wssDNj

Section 02

LONG COVID IN CHILDREN & YOUNG PEOPLE



How common is Long Covid?

Public messaging and information dissemination is now more crucial than ever. COVID-19 is airborne and it is not a seasonal virus. We also now have multiple reports of reinfections captured both anecdotally and recorded in UK government data.

In the UK we benefit from the ONS prevalence estimates which currently indicate that 119,000 children and young people are living with Long Covid; 21,000 of whom are still experiencing symptoms after 12 months. It is pertinent to note that anecdotal evidence indicates symptom duration is continuing from first wave infections to date.

Prevalence estimates from research vary. This is because different studies use different methods. For example:

- The symptoms the researchers choose to study
- The number of symptoms
- The symptom duration
- How a case is determined
- Calculations based on all children infected or all children in the population
- Definitions of relapsing and remitting symptoms
- Use of a control group and how robust the control group is

Until we have a worldwide agreed definition for paediatric Long Covid and formally count prevalence, the scale of the burden will always remain unclear. While our international friends work with the UK towards a clinical case definition for children, the World Health Organisation has provided us

with the first clinical case definition for Long Covid in adults.



Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually three months from the onset of COVID-19 with symptoms and that last for at least two months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.

If any symptom comes and goes, or persists for more than four weeks after infection, especially when part of a constellation, **Think Long Covid.**

We must be cautious with the health of our children. We are told that we must learn to live with COVID. The only way to prevent Long Covid is to prevent SARS-CoV-2 infection in the first place.

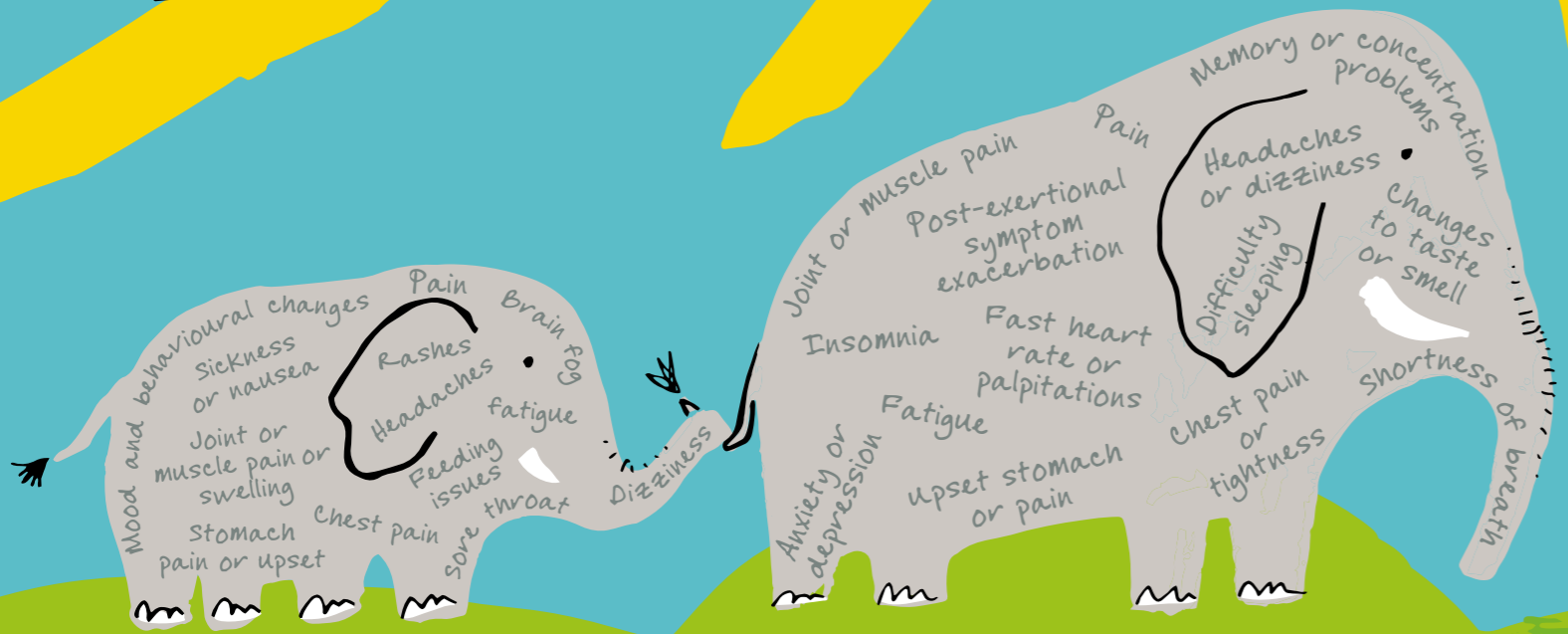


WHO definition for Long Covid in adults
bit.ly/36EgfyC

LONG
COVID
KIDS

Shining a light on

LONG COVID



longcovidkids.org

The size of the problem...

A summary of UK and England data totals from the start of the pandemic running to 1 April 2022.

COVID-19 cases

As a % of the **number of people*** in each age group. England UKHSA. Total to **13 March 2022**

12%
of all 0-4
year olds

30%
of all 5-9
year olds

44%
of all 10-14
year olds

41%
of all 15-19
year olds

*bit.ly/3qkrNy1

Hospitalisations

Number of new admissions to hospital of patients with COVID-19. England, **UKHSA total*** to **15 March 2022**

3.2%
of all COVID-19
hospitalisations have
been children & young
people age 0-17

In recent months
relatively more
children have been
hospitalised

In 2022
6.7%
of all COVID-19
hospitalisations
are children &
young people

9 consecutive months
with more than
1,000
children hospitalised
with COVID-19, from
July 2021 to March 2022

*bit.ly/37OrtBz

Deaths

involving COVID-19 (0-19) ONS, England & Wales, **registered by* 5 March 2022**

106
deaths

Between July 2021
and January 2022,

813 (5-19)
died due to any
cause**.

5.3%
of all deaths involved
COVID-19, comparable
with the 7% of all
adult deaths in the
same period involving
COVID-19

86%
of those (5-19)
deaths had COVID-19
as the underlying
cause of death

*bit.ly/3ljchZy
**bit.ly/3JCEwni

Long Covid (ONS, UK)* four week period ending **31 January 2022**

Symptoms for at
least 4 weeks (2-16)

119,000

Symptoms for at least
12 months (2-16)

21,000

11.8%

of 2-16 year olds
experiencing Long
Covid say it limits
their activity a lot

*bit.ly/3ubO6qT

All data are sourced from official statistics, with analysis by James Neill

Long Covid symptoms in children

Central nervous system

This part of the body is made up of the brain and spinal cord. It takes in information from the body, processes it and then produces the body's responses.

- Brain fog/cognitive disturbances such as poor concentration, confusion, short-term memory problems, memory loss, word finding difficulties or word repetition
- Mood changes
- Depression
- Anxiety
- Headache and migraine
- Lightheadedness
- Dizziness
- Unexplained irritability
- Tics and twitches
- Stuttering, swearing, vocalising
- Behavioural changes
- Difficulty regulating temperature
- Tremors
- Sleep issues
- Suicidal thoughts

Respiratory system

The network of organs and tissues that help a person to breathe.

- Shortness of breath
- Wheezing
- Breathing pattern disorders
- Chest pain
- Cough
- Sore throat
- Throat clearing
- Throat tightness
- Voice changes

Endocrine system

Consists of a number of different glands and organs which produce and regulate hormones to control many functions of the body.

- Hormonal imbalance
- Menstrual changes
- Menstrual pain/cramping
- Worsening premenstrual syndrome
- Testicular pain

Gastrointestinal system

Responsible for processing foods, absorbing nutrients, and eliminating waste.

- Abdominal/stomach pain/cramps
- Bloating
- Diarrhoea
- Nausea/vomiting
- Gastric reflux
- Food restriction and weight change

Integumentary system

Consisting of the skin, eyes, glands, hair and nails, it protects the internal body from the outside world.

- Fever
- Swollen glands/lymph nodes (throat, under arms, groin)
- Reduced antibody reaction
- Histamine intolerance
- Mast cell diseases
- Pallor (pale skin)
- Skin rashes
- Skin flushing
- Itchy skin
- Excessive sweating
- Peeling skin
- Red/cracked lips
- Hair loss
- Ulcers

The symptoms of Long Covid listed below have been evidenced in paediatric research. We have also included symptoms observed in our Support Services, many of which are evidenced in adult research. **If any symptom comes and goes, or persists for more than four weeks after infection, especially when part of a constellation, Think Long Covid.**

Musculoskeletal system

Provides the body with support, stability and the ability to move. It consists of bones, joints, ligaments, muscles, tendons, cartilage and bursa.

- Joint pain
- Muscle aches
- Swelling
- Joint redness
- Connective tissue disorders

Whole body

- Pain
- Tiredness and weakness
- Fatigue
- Insomnia
- Excessive sleepiness
- Insomnia
- Flu-like symptoms
- Post exertional symptom
- Exacerbation (PESE)
- Self harm/suicidal thoughts
- Food restriction
- Weight loss or weight gain
- Difficulty regulating temperature
- Dental and gum problems

Renal system

A group of organs that work together to store, release and produce urine

- Acute kidney injury
- Urinary frequency
- Urinary hesitancy

Cardiovascular system

This system is made up of the heart and blood vessels.

- Chest pain/tightness
- Myocarditis/Pericarditis
- Heart palpitations
- Increased heart rate (Tachycardia)
- Bradycardia and arrhythmias

- High or low blood pressure
- Fainting
- Oxygen desaturation
- Inflammation
- Blood vessel damage
- Coagulopathy (excessive bleeding or clotting)
- Microangiopathy (Covid toes)
- Nose bleeds
- Anaemia

Sensory system

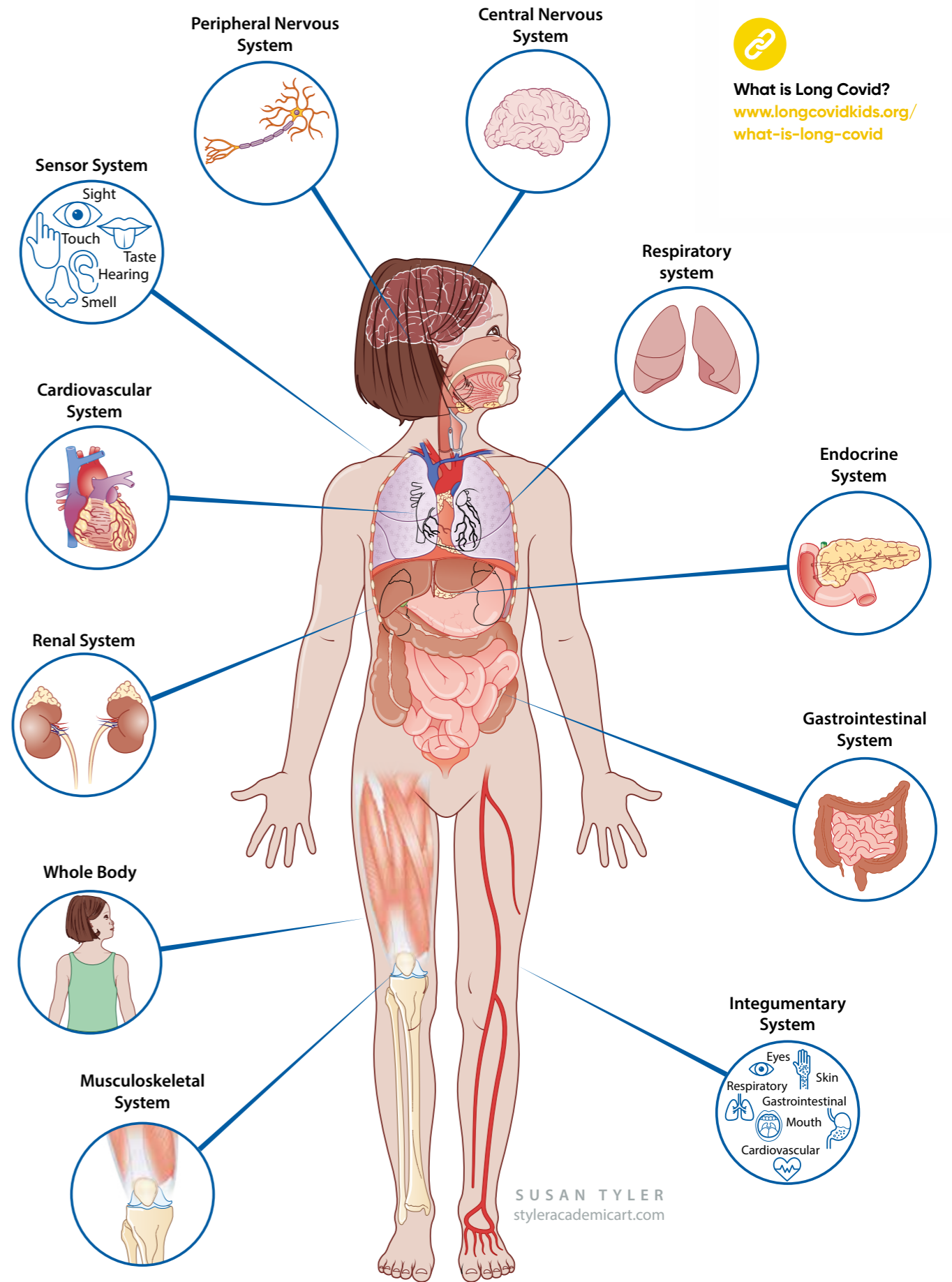
Part of the nervous system responsible for processing information from our senses

- Tinnitus
- Earaches
- Noise sensitivity
- Nasal congestion
- Loss/change of smell
- Phantom smells
- Loss/change of taste
- Loss of appetite
- Difficulty swallowing
- Red eyes/conjunctivitis
- Blurred vision
- Light sensitivity

Peripheral nervous system

This system consists of all the nerves branching out from the brain and spinal cord

- Pins and needles
- Numbness
- Swollen hands/feet
- Dysautonomias, eg. POTS
- Fainting
- Tics and twitches
- Tremors
- Difficulty regulating temperature



What is Long Covid?
www.longcovidkids.org/what-is-long-covid

References

[bit.ly/3i2ZdNa](https://doi.org/10.1101/2023.03.15.23281111) Clinical Characteristics, Activity Levels and Mental Health Problems in Children with Long COVID: A Survey of 510 Children[v1] | Preprints [bit.ly/35Q31Pq](https://doi.org/10.1101/2023.03.15.23281111) Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study | British Journal of General Practice (bjgp.org) [bit.ly/3t7bR4k](https://doi.org/10.1136/bmj-2022-075444) Post COVID-19 in children, adolescents and adults: results of a matched cohort study including more than 150,000 individuals with COVID-19 | medRxiv

The lived experience

Anna

by mum Helen

Anna's first COVID19 infection was late March 2020, age 7, when she had mild symptoms and seemed to recover well. Four weeks later Anna developed a sudden high fever of 39-40 degrees, widespread rash, extreme light sensitivity, puffy hands and feet, cracked red lips, severe headache and nausea. She couldn't eat or drink, was frequently difficult to rouse from sleep and unable to walk the short distance to the bathroom.

At the time, Government messaging stated not to attend hospital under any circumstances without prior permission. NHS 111 would not allow Anna to be seen despite her being desperately unwell. On day eight, the fever broke and Anna began to recover very slowly. **She has since had a backdated clinical diagnosis of PIMS.**

Anna's PIMS symptoms receded but were replaced by overwhelming fatigue, severe sleep disturbances, swollen glands, frequent nausea, intermittent severe abdominal pain, severe headaches, peeling skin, continued rash, audio hallucinations, alarming mood swings with rage and aggression, vocal and motor tics, severe sensitivity to light, noise and other sensory processing difficulties. Hospital tests revealed only an iron and vitamin D deficiency, however **she was diagnosed with Paediatric Acute Onset Neuropsychiatric Syndrome (PANS).** Anna was unable to return to school and was enrolled in online education provision.

In July 2021 Anna had a second COVID-19 infection and was unwell with a fever and malaise. On recovery, Anna's Long Covid



symptoms worsened and the PANS symptoms were so severe that the family had to seek private healthcare in the absence of NHS treatment. New physical symptoms emerged and Anna struggled to walk for any distance without pain in her legs and feet. She now requires a wheelchair for support.

Two years on and Anna hasn't recovered.

She is mostly housebound and hasn't been able to attend online school since her second infection. She hasn't seen her friends, or enjoyed her hobbies for over a year and she struggles to attend medical appointments. Anna's mental health is suffering due to being chronically unwell for a significant portion of her life. Now, age nine, her childhood is slipping away and she is losing hope for recovery.

www.longcovidkids.org/post/helen-anna-s-story-long-covid-kids-scotland

The lived experience

Jacob

by mum Victoria

March 2021.

Meet Jacob. He's not feeling good, he's restless. **Negative LFT**

Two weeks later, Jacob's not improving. He's shuffling, not walking and taking stairs on his bottom.

GP advised mum, Victoria, to wait and review after six weeks. He's not attending school. **His PCR is negative.**

After bloods taken at A&E, Jacob is worsening: tired, limp, chest pains, tingling hands and legs. His face is grey with dark bags under his eyes.

Bloods come back clear.

Weeks pass. The GP calls for an update. Jacob's now crawling because his legs hurt so much. At A&E more bloods and routine tests done. The nurses make him walk. Consultant makes him walk more, then hop on one leg. Jacob grabs his calf like he's pulled it.

Consultant looks confused. Bloods normal. No temperature, no vomiting, no diarrhoea. No positive test, no Covid he says sternly. **It's psychosomatic**, he says.

Jacob's crying. **"I knew they wouldn't believe me"**. He sobs. He grabs his T-shirt. He's having a panic attack.

Another appointment, another paediatrician. Jacob's in a wheelchair. All test results are normal, she says. Mum raises POTS and consultant agrees to 24hr ECG. Again, normal.

But his dizziness continues. A POTS specialist prescribes medication and in two weeks Jacob improves. Not limp, not weary. But still not walking.



Tilt test done, inconclusively and, it seems, wrongly.

No progress with neurologist, MRI clear, refuses further tests.

Private neurologist **confirms Long Covid**. Further nerve damage investigations are pending.

Evenings, he's great, but in constant pain.

Jacob managing to walk with his mobility aid
www.youtube.com/watch?v=DBUBvaCj8N0
Need link to Jacob's blog

The lived experience

Rosie

by dad Colin

3 September 2021, the third day of Rosie's AS levels. 'PING' – she was a close contact.

Two negative PCR's later, she lost her taste and for a couple of nights had a bit of a temperature.

17 March 2022, she should have been performing with her Irish dance school for St Patrick's Day. Instead, I wheeled her through Belfast Airport in a chair to go to her Great Uncle's memorial. He died from COVID-19 in April 2020.

In six months, Rosie managed about eight half days in school. She is trying to complete her AS level Art. But it's a struggle. **The effort of sitting upright to paint or work on her portfolio causes crushing fatigue.** The cognitive effort of researching artists causes her lingering migraine to flare up unbearably.

She struggles to write a few sentences. Shortly after, she can't remember what she has written.

In August 2021, she got 9 A and A* grade GCSEs.

Rosie can still make art, in short bursts. It's her remaining passion. She aims to start an Art and Design course in September. A whole year of her life stolen away by the lingering effects of this awful virus.

She hopes to dance again; for now that's very distant. She is not getting better despite thousands spent on private appointments



and tests. She has POTS. She has muscle pain. For now, they make walking almost impossible, let alone a treble reel or a slip jig.

My heart breaks for her. Every single day.

How children describe Long Covid



Supporting wellbeing

When feeling unwell for a long period of time it is normal for children to encounter difficult emotions and experiences.

The best way to support children and young people to manage difficult emotions and experiences is by helping them to focus on what they can control. Provide support to help children take small steps to boost their happiness, connections with others and to notice their strengths and achievements.

01

Connecting with others

When we feel valued and have positive relationships with those around us we tend to feel more connected, secure and happy. Little ways to connect with others could simply be:

- Smiling at someone or giving them a compliment
- Reaching out to someone new who has a shared experience or shares a common interest
- Taking time to really 'hear' others
- Playing a game with siblings or friends
- Joining in with a fun activity.



Action for Happiness produce monthly calendars to help children and young people connect with others and spread kindness.
www.actionforhappiness.org/calendars

02

Taking notice

Being aware of thoughts and feelings and taking notice of what is around you can boost wellbeing. Small ways to take notice could be:

- Notice your thoughts and feelings
- Practice mindfulness, yoga or meditation techniques where you can pause, focus on your breathing and achieve a sense of calm
- Notice colours, sounds, smells, shapes and textures of everyday things around you
- Notice sights, sounds and smells when outside in nature.

Useful resources



Smiling Mind App
www.smilingmind.com.au/smiling-mind-app

Three Good Things Gratitude Practice
www.elsa-support.co.uk/three-good-things-gratitude-practice/



Mindfulness Exercises for Children
www.jwbridgethegap.com

03

Giving

Giving to others, being kind and sharing our skills, time or resources can give us a sense of purpose, a sense of belonging and is good for our wellbeing. Small acts of kindness could involve:

- Doing something kind for a friend, classmate or adult in school
- Thanking someone, smiling or giving a compliment
- Raising money for a charity event
- Donating your old toys, books, sports equipment, clothes, etc. to a local charity.

Useful resources



Relax Kids
www.relaxkids.com

Diary of a journal planner
www.diaryofajournalplanner.com

Cosmickids
www.cosmickids.com

Youth Wellbeing Directory
www.annafreud.org

YoungMinds
www.youngminds.org.uk

Elsa Support
www.elsa-support.co.uk

04

Enjoying activity

Movement and activity are proven to boost feelings of wellbeing and are also associated with lower rates of low mood. Activities can be big and organised, or small and essential.

Living with Long Covid can make movement and activities more challenging for some people. Enjoy movement, but cautiously, taking time to work out what feels right. Be aware that doing too much or 'pushing through' fatigue can make symptoms worse.

Useful resources



Long COVID Physio
bit.ly/352ldVw



Mind
physical-activity-and-your-mental-health-2019.pdf
(mind.org.uk)

Syndromes associated with post viral illnesses including Sars-CoV-2

Introduction to this section could go here

PIMS-TS: Paediatric Inflammatory Multisystem Syndrome temporarily associated with SARS-CoV-2

Overview

PIMS-TS is a new systemic inflammatory disease that mainly affects children. It is referred to as Paediatric Inflammatory Multisystem Syndrome in children and Multisystem Inflammatory Syndrome in children (MIS-C) in the US and Internationally.

PIMS-TS causes serious inflammation throughout the body. Inflammation is a normal chemical triggered response of the body's immune system to fight infection. However, sometimes the immune system can go into overdrive and begin to attack the body.

What we know

For a disease to be classed as rare it affects less than 1 in 2000. Since March 2020 there have been almost 3000 cases of PIMS-TS in the UK alone.

Symptoms of PIMS-TS are different to COVID-19. Many children who experience PIMS-TS may not have previously been unwell with COVID-19 or had asymptomatic infection. The symptoms of PIMS-TS generally don't appear until four to six weeks after SARS-CoV-2 infection. Children can seem to recover from the acute infection and then develop PIMS-TS. As with Long Covid a positive COVID-19 test is not essential for diagnosis. Knowledge of exposure to COVID-19 helps diagnosis.

Where can I learn more?



What is PIMS?
bit.ly/3lpK2lO
bit.ly/355nEGV
bit.ly/3qvs9Sy

Symptoms

PIMS-TS is commonly misdiagnosed because it is new and because symptoms are similar to other childhood conditions. However, all children with PIMS will have a fever (>38 degrees), which persists over several days and may not reduce with over-the-counter medications. Tell your medical professional if your child is likely to have been exposed to COVID-19.

There's a wide range of other symptoms that children might have, including:

- Rash
- Tiredness, sleepiness or fatigue
- Muscle pain
- Tummy pain or cramps
- Red and cracked lips, often swollen
- Strawberry tongue
- Swollen fingers, toes or hands and feet, often red
- Cold hands and feet
- Peeling skin on hands and feet
- Headache
- Red bloodshot eyes
- Muscle aches and pains
- Diarrhoea and vomiting
- Racing heart
- Dizziness
- Swollen neck glands
- Unexplained irritability.

While most won't be seriously unwell with COVID-19 acute infection, some children may develop PIMS-TS. The most important thing is to remember that any child who is seriously unwell needs to be treated quickly – whatever the illness. If you suspect PIMS-TS take your

PIMS-TS: Paediatric Inflammatory Multisystem Syndrome temporarily associated with SARS-CoV-2

child to Accident and Emergency as soon as possible.

You may already have had nose and throat swabs to confirm you had COVID-19 but PIMS develops after the virus is infectious and so a PCR test will likely be negative at the time. The doctors will rule out other more common conditions that cause similar symptoms – this includes things like Kawasaki Disease, Sepsis and Toxic Shock Syndrome.

Diagnosis and treatment

Blood tests look at the levels of inflammation in the body as well as checking how various parts of the body are working. Together, these results along with your symptoms let the doctors confirm you have PIMS so they can treat it.

PIMS can be treated with a combination of medicines to reduce inflammation in the body and temporarily 'switch off' the hyperactive immune system:

- Intravenous immunoglobulin (IVIG).
- Corticosteroids
- Anti-clotting medicines (aspirin and dalteparin)
- Biologic medicines (Anakinra and Tocilizumab)

We don't yet know enough about how frequently children who get PIMS-TS go on to experience Long Covid. Long Covid Kids have been highlighting in official meetings that non-hospitalised presentations consistent with PIMS have been seen in their Support Group since 2020. **See blog for further details on recovery from PIMS-TS and Long Covid.**

Syndromes associated with post viral illnesses including Sars-CoV-2

PANS: Paediatric Acute-Onset Neuropsychiatric Syndrome

Overview

PANS is a neuropsychiatric condition which is not well known or understood within the medical community, with little guidance provided by healthcare organisations. You may also see the term 'PANDAS' which relates to a subset of PANS, associated specifically with streptococcal infections.

What we know

PANS is a condition triggered by a misdirected immune response to either an infection or an immune, inflammatory or metabolic cause, resulting in a constellation of neuropsychiatric symptoms. A number of infections are known to trigger PANS such as influenza, hand, foot and mouth disease, chicken pox, pneumonia, and more recently COVID-19 infection. PANS is not a rare condition however it is little understood and underdiagnosed – accessing help and support can be challenging.

PANS can appear after apparent recovery from acute COVID-19. One day a child is well and over the next week or so they may display overwhelming symptoms. Some children with PANS triggered by COVID-19 infection may not be easily identified, particularly if they have experienced an asymptomatic COVID-19 infection. The defining feature of this condition is its immediate onset, although a less dramatic onset has been reported with earlier 'soft signs'. Children with PANS can change in personality and behaviour almost overnight which can be very frightening for the child and their family.

Symptoms

For a patient to be diagnosed with PANS, they must have experienced an abrupt, acute, dramatic onset (usually within 24-48 hours) of:

- **OCD** (for example, a constant need to wash hands, order and arrange things, constantly seek reassurance, repeat movements or sounds, intrusive thoughts). **Or**
- **Severely restricted food intake** (this can be due to obsessional fears, difficulty with swallowing or fears of contamination. Children with eating disorders arising from PANS do not generally respond to the usual treatments for other eating disorders).

Along with two or more of the following symptoms, which are not better explained by a known neurologic or medical disorder:

- **Anxiety** (heightened anxiety, separation anxiety, irrational fears, panic episodes)
- **Tics** (verbal and/or motor)
- New **sensory abnormalities** (sensitivities to light, noise, smell, taste or texture)
- New **motor abnormalities** (e.g. clumsiness or Dysgraphia (difficulty with handwriting))
- **Sudden deterioration in school performance** due to cognitive changes and memory deficits, hyperactivity impulsivity, new deficits of visuospatial skills
- **Emotional lability** (extreme or exaggerated changes in mood or emotions, which fluctuate rapidly and are not always appropriate to the situation) and/or depression.
- **Irritability, aggression, and/or severely oppositional behaviours**
- **Behavioural (developmental) regression** (increase in temper tantrums, loss of age-appropriate language, clingy

behaviour not related to anxiety).

- **Sleep disturbance** (insomnia, waking at night, difficulty rising, nightmares or needing to sleep close to their parent/caregiver)
- **Urinary incontinence (loss of bladder control) or urinary frequency.**

Whilst not part of the diagnostic criteria, there have been reports of psychosis and/or hallucinations. Additionally, new phobias, trichotillomania (hair pulling), enlarged pupils, tiredness or painful joints are reported

It may be more difficult to identify PANS in children and young people with pre-existing neurodivergences, learning disabilities or neurological or mental health conditions due to them already experiencing some of the symptoms listed above. In this case look for the sudden addition of new or worsening of existing symptoms.

PANS symptoms can also affect children at school. The hallmark of this condition is an unexplained change in a child's presentation. Children can quickly go from thriving to developing Special Educational Needs and Disabilities (SEND). Schools are uniquely placed to spot the early signs of the condition and should be aware that early educational intervention leads to better outcomes.

Diagnosis and treatment

PANS is a clinical diagnosis based on history taking and there are currently no specific tests which will conclusively identify the condition. Your GP may refer your child to Paediatrics and/or CAMHS for further assessment and tests to exclude other diagnoses.

PANS: Paediatric Acute-Onset Neuropsychiatric Syndrome

With thanks to Vicky Burford

Chair of Trustees
PANS PANDAS UK

Blood and urine tests, swabs, MRI and EEG may be used to rule out other conditions based upon medical and family history.

If you suspect your child has developed PANS, it can be useful to take detailed notes of daily behaviour since the onset of symptoms to show to your GP alongside the GP Information Leaflet collated by the PANS PANDAS UK Charity. PANS can be treated successfully, but early intervention is crucial.

The lack of NICE guidelines in the UK is leading to a lack of clarity and guidance. UK clinicians are not currently supported to follow the USA or Nordic countries clinical guidelines which are centred on treating ongoing verified infections or suspected inflammation, treating immune focused issues alongside the mental health symptoms using:

- Antibiotics
- Anti-inflammatories
- Short course of steroid therapy
- Intravenous immunoglobulin (IVIG)
- OCD often benefits from CBT or counselling

More research into COVID-19 and PANS is urgently needed alongside developing NICE clear evidence-based treatments in the UK.

Where can I learn more?

LCK PANS Blog
URL

PANS PANDAS UK (UK)
www.panspandasuk.org/

PANDAS Network (US)
www.pandasnetwork.org/

Syndromes associated with post viral illnesses including Sars-CoV-2

PoTS: Postural Tachycardia Syndrome

Overview

Postural Tachycardia Syndrome (PoTS) is a collection of symptoms (syndrome) which include tachycardia (fast heart rate) which varies due to the position of the body (postural) and particularly increases in the upright position (orthostatic) with symptoms reducing on lying. It is therefore also sometimes known as postural orthostatic tachycardia syndrome.

What we know

PoTS is a syndrome caused by a malfunction of the autonomic nervous system, the system that regulates our involuntary bodily functions such as breathing, heartbeat, blood flow, breathing and digestion. It is one of the conditions which comes under the umbrella of dysautonomia.

Normally when you sit up or stand, gravity pulls some of the blood downwards in the body and your body adjusts to regulate this. With PoTS this regulation does not happen automatically. When a person stands or sits up there is a drop of blood supply to the heart and brain and the heart beats faster to compensate. **"A person with PoTS uses three times more energy to stand than normal. Even minor movements can be exhausting and increase symptoms."**

Standing Up to PoTS:
www.standinguptopots.org/livingwithpots/what-is-pots

PoTS affects a range of people but is most commonly diagnosed in girls and women aged 15 to 50.

There are a number of triggers including puberty, viruses or a traumatic event and recent studies suggest a link between PoTS and COVID-19 infection.

Symptoms

The symptoms of PoTS are numerous and the intensity/duration of symptoms can vary. Some people have mild symptoms, while others find the condition greatly affects their quality of life.

- Fast heart rate (faster when standing or sitting upright than when laying down)
- Fatigue
- Breathlessness, even with small amounts of exertion
- Tight chest and palpitations
- Feeling dizzy and/or lightheaded when standing up
- Fainting
- Headaches and/or migraines
- Brain fog
- Sweating
- Nausea
- Gastrointestinal problems

Some triggers are known to worsen symptoms:

- Excessively hot environment/clothes
- Sudden change in position, particularly standing up quickly
- Early morning after waking up compared to later in the day
- Exercise (although small amounts of regular exercise may actually improve symptoms)

Diagnosis and treatment

Diagnosis is often made by a cardiologist, neurologist or paediatrician, although not

all of these specialise in the condition. Generally to be given a diagnosis of PoTS, a person needs to have:

- PoTS symptoms mostly when upright for three months or more
- A sustained increase in heart rate of greater than 30 beats per minute within 10 minutes of standing (40 beats per minute for those aged 12-19).

These criteria may not apply to those with a low heart rate when resting. There is usually no drop in blood pressure on standing.

The Active Stand (also known as the Nasa Lean Test) is used to diagnose PoTS. Some people may undergo a Head-Up Tilt Table Test but these are not available at all hospitals.

A specialist may also give a diagnosis in cases where the above criteria is not quite met but the person remains clearly symptomatic with typical symptoms when upright.

An ECG (Electrocardiography) is performed to rule out any heart problems that may cause symptoms similar to those found in PoTS.

Other tests that might be helpful are wearing an ambulatory blood pressure and heart rate monitor for a period of 24-72 hours or having an Echocardiogram (heart ultrasound) to check if the structure of the heart is normal. A 24-hour urine collection and various blood tests may be used to rule out other conditions. Autonomic function screening tests require a special laboratory and are not available in most hospitals.

PoTS: Postural Tachycardia Syndrome

With thanks to Dr Lesley Kavi

Visiting Professor, Birmingham City University
RCGP Syncope Clinical Champion
Trustee and chair, PoTS UK

PoTS often improves gradually over time, although there are some medicines and self-care measures that can help.

The treatment of PoTS can vary depending on how it affects the child or young person. There is no cure but it can be managed effectively. PoTS UK is a great resource for management of symptoms using:

- Increased fluid and salt intake (unless contraindicated)
- Breathing techniques to manage breathing pattern disorders
- Compression clothing
- Fatigue management
- Lifestyle adaptations
- Appropriate exercise (please be aware of cautions if also experiencing PESE)
- Mental health support
- Medication: this is usually used after the above strategies have been trialled. There are no current medications "approved" for use with PoTS and so the ones that are used are 'off-licence'. They need to be considered carefully and with monitoring for side effects. In the end a risk/benefit analysis will be done to see whether to continue with any medication trialled. Some people do have extremely positive reactions to medications.

Where can I learn more?

LCK PoTS Blog - URL
NHS (UK)
www.nhs.uk/conditions/postural-tachycardia-syndrome/
PoTS UK (UK)
www.potsuk.org/
Standing Up to PoTS (US)
www.standinguptopots.org/

Syndromes associated with post viral illnesses including Sars-CoV-2

ME/CFS: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Overview

Myalgic Encephalomyelitis (ME) is a serious, complex, fluctuating, chronic neurological condition. It is also referred to as Chronic Fatigue Syndrome (CFS) or ME/CFS – although there is debate over the appropriateness of these terms. In some countries, ME is not recognised as a physical illness, with some professionals still believing the condition is psychological in nature, despite growing evidence to the contrary.

What we know

The cause of ME is not currently known, however research into the mechanisms causing symptoms is ongoing.

ME is often triggered by a virus, such as glandular fever or seasonal flu, although other documented triggers include injury and surgery. It can affect people of any age, including very young children. It is diagnosed more in women than men (approx ratio of 4:1). It varies in severity and can be classified as mild (able to attend school/work some of the time with adequate rest), moderate, severe or very severe (mostly in bed).

The recovery rate for children is not clear but anecdotal evidence indicates that with appropriate early management, recovery is possible.

Symptoms

- Profound fatigue & Post Exertional Malaise (PEM)/Post Exertional Symptom Exacerbation (PESE) – which is a worsening of symptoms after activity.
- Sleep issues
- Muscle weakness, muscle and joint pain
- Flu-like symptoms such as sore throat and headaches
- Brain fog (eg. word finding difficulties, clarity of thought)
- Memory problems
- Issues with temperature regulation
- Dizziness, PoTS, orthostatic intolerance
- Digestive issues (IBS type symptoms)
- Sensory sensitivities (e.g. to light and sound)
- Allergies
- Worsening of premenstrual issues, and other female specific comorbid conditions such as endometriosis.

Many of the symptoms overlap with symptoms of Long Covid, however the relationship between the two conditions needs further research before conclusions can be reached. There will be benefits in researchers looking at both conditions, working together.

Diagnosis and treatment

Many people with ME struggle to have their symptoms taken seriously and it can end up taking quite a long time to receive a diagnosis. This is not helped by the absence of specific diagnostic tests.

The key symptom required for diagnosis of ME is PEM/PESE which can be identified via

self-report on a screening questionnaire. CPET is an objective two-day cardiopulmonary exercise test where performance in two exercise tests is completed 24 hours apart. The comparison in how the body responds or functions has been shown in research to be notably different in people with ME, although this test is not routinely offered.

There are currently no specific medical or rehabilitative treatments recommended for ME. The 2021 review of the NICE guidelines removed the recommendation for treatment using Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT).

Medical professionals can instead aim to improve quality of life and functioning by managing the symptoms of the condition and its commonly co-occurring conditions. Some alternative therapies such as acupuncture may benefit some individuals in terms of their symptom management but more research is needed to demonstrate this objectively.

Pacing and other energy management techniques (e.g. spoon theory, energy envelope, heart rate monitoring) are often used as a management method. These strategies generally become a way of life for people with ME and should not be considered curative, although pacing can support improvements in the ability to function for some people.

ME/CFS: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

With thanks to Dr Nigel Speight

Paediatrician with a special interest in ME, adviser to Tymes Trust, 25% Group and MEA Member of Doctors with ME and Forward ME

Where can I learn more?



LCK ME/CFS Blog

URL

NICE Guidelines (UK)

www.nice.org.uk/guidance/ng206

CDC (US)

www.cdc.gov/me-cfs/symptoms-diagnosis/symptoms.html

ME Association (UK)

www.meassociation.org.uk/

ME Action (International)

www.meaction.net/

Long COVID Physio

bit.ly/352ldVw

Long COVID Physio

bit.ly/3Np4nBM

Syndromes associated with post viral illnesses including Sars-CoV-2

MCAS: Mast Cell Activation Syndrome

Overview

Mast Cell Activation Syndrome (MCAS) is a collection of symptoms linked to a hyperactive allergy response from the body. These symptoms of inflammation happen frequently and often in response to triggers not usually considered harmful. For some people their body's response to these triggers can lead to anaphylaxis.

What we know

Mast cells are a type of blood cell found in all body tissues. They help protect the body by detecting threats like bacteria, viruses and toxins by releasing chemical 'mediators' (e.g. histamine, prostaglandins, etc.) that help to organise an immune response. Unfortunately, in MCAS, the mast cells are easily activated, releasing their chemical mediator to often unhelpful triggers. This leads to many unwanted symptoms in various body systems.

People with MCAS often have comorbid conditions such as Ehlers Danlos Syndrome (EDS), type two diabetes or Dysautonomias, such as PoTS.

Symptoms

Multiple symptoms can be experienced, across body symptoms. They range in severity from unpleasant to debilitating and can include the medical emergency anaphylaxis. They may come and go, and change in severity, moving from mild to an increased severity or frequency if the immune system is triggered.

- **Neurological** – headache, brain fog (memory and concentration difficulties), numbness, pain or tingling skin, anxiety, behavioural issues, rages
- **Cardiovascular** – chest pain, low blood pressure, fast heart rate, fainting or lightheadedness
- **Gastrointestinal** – bloating, stomach cramps or pain, reflux, feeling or being sick, diarrhoea, constipation, dumping syndrome, food allergies or intolerance
- **Nasal-Ocular** – nose congestion, eye watering and itching
- **Respiratory** – sore throat, hoarseness, wheezing, shortness of breath, throat swelling
- **Musculoskeletal** – joint and muscle pain, osteoporosis (brittle bones), loss of bone mass
- **Genital/Urinary** – genital pain or swelling, pain when urinating, vaginal pain, discharge or itching, bladder urgency or loss of control
- **Dermatological** – flushing, redness, hives or wheals, itching with or without a rash, swelling
- **General** – extreme tiredness; anaphylaxis, which can be life threatening.

Recognising anaphylaxis

This is a serious allergic/hypersensitive reaction to a trigger (common ones are food, stinging insect venoms, drugs).

- Rapid onset (minutes to hours) of symptoms involving the skin or inside the mouth or nose (e.g. hives, swollen lips or tongue)
- Breathing difficulties
- Reduced blood pressure, collapsing, incontinence
- Persistent gastrointestinal symptoms (e.g. cramps or vomiting)

Diagnosis and treatment

MCAS is another condition that is not routinely recognised. It is not uncommon for people with MCAS to spend several years being referred from specialist to specialist, yet stay undiagnosed.

- First symptoms need to be recognised (which can be difficult as they overlap with other syndromes).
- The next step is often to test treatments, such as antihistamines, antiprostaglandins or mast cell stabilisers.
- Mediator-tests (*via blood or urinary tests) should be completed by an experienced provider, however timing these tests to occur during a symptomatic flare up of MCAS can be difficult. There is no single test that can definitively diagnose MCAS – this information is used in conjunction with the other steps.
- The final step is to rule out other diagnoses.

Trigger Avoidance

Self-management through avoidance of triggers – where they are easily identified and avoided. This is not always feasible.

Special diets such as low-histamine or FODMAPS may help – it is best to speak to a dietician or nutritionist who is aware of MCAS for advice.

Medications

Medications are available but they should be trialled under medical guidance, so even for over-the-counter medications it is best to check with your healthcare provider on appropriateness and dosage. For some people certain medications or excipients

MCAS: Mast Cell Activation Syndrome

With thanks to Isaac Osobukola

Medical Science Liaison Intern
at Mast Cell Action

(colouring agents, preservatives and fillers) can trigger a flare-up of their MCAS.

It is best to keep a symptom diary and medications may be added in one by one to ensure any beneficial effect is attributed to the correct medication.

Where can I learn more?

LCK MCAS Blog
[URL](#)

Mast Cell Action (International)
www.mastcellaction.org/about-mcas

American Academy of Allergy, Asthma and Immunology (US)
www.aaaai.org/conditions-treatments/related-conditions/mcas

Proposed diagnostic algorithm for MCAS in children
www.ncbi.nlm.nih.gov/pmc/articles/PMC7911219/pdf/medicina-57-00124.pdf



Syndromes associated with post viral illnesses including Sars-CoV-2

FND: Functional Neurological Disorder

Overview

Functional Neurological Disorder (FND) describes a wide range of neurological symptoms relating to movement and sensation in the central nervous system such as paralysis, seizures, tremor, movement disorders and numbness. FND commonly occurs alongside other medical, neurological and psychological disorders.

What we know

FND relates to a problem in nervous system functioning rather than structural damage that can be seen with conventional scans or blood tests. It is diagnosed on the basis of typical clinical features which, for example, show that people with FND have trouble with voluntary movements but have better 'automatic' movements. Functional seizures also have typical features which allow neurologists to differentiate them from epileptic seizures.

FND is commonly triggered by other medical illness, including Sars-CoV-2 but can also be triggered by physical injury, pain or in some cases, severe stress. FND has been stigmatised and misunderstood over a long period but in recent years renewed interest in the disorder has seen a new understanding as a disorder at the interface between neurology and psychiatry which affects up to 100,000 people in the UK and needs a multidisciplinary approach.

Symptoms

FND can cause many different symptoms including:

- Limb weakness, paralysis and walking difficulties
- Tremor, jerks, tics or limb spasms (dystonia)
- Seizures or episodes that look like faints
- Visual loss and double vision
- Speech problems including stuttering and slurred speech
- Numbness, pins and needles
- Persistent dizziness
- Cognitive symptoms

People with FND commonly have other symptoms including pain, fatigue, bowel and bladder symptoms which may relate to other functional disorders.

Anxiety, panic attacks, post-traumatic stress symptoms and depression are common in people with FND. However, many people with FND have no psychological problems and their condition has not arisen primarily due to stress.

Diagnosis and treatment

Neurologists look for specific positive features on clinical assessment that allow them to make a diagnosis of FND. In other words, it is not a 'dustbin diagnosis' when tests are normal. Positive diagnostic features include Hoovers sign and Hip abductor sign for limb weakness, tremor entrainment test for tremor and assessment of gait at varying speeds and during other tasks. Investigations are important to look for concomitant neurological condition

Treatment involves initially helping young people and their families to understand the diagnosis and that there is a 'software' problem in the brain rather than a 'hardware' issue. Functional neuroimaging and other neuroscience studies have, in recent years, been able to show this is happening for the first time. Treatment should be multidisciplinary and can involve any of neurology, physiotherapy, psychological therapy, psychiatry, occupational therapy, speech and language therapy, depending on the nature of the symptoms.

Randomised controlled trials have shown benefit for these treatments. The FND Society (fndsociety.org) has 1000 members internationally and research in FND has grown significantly in recent year.

Where can I learn more?

Further information is available from patient-led organisations such as fndhope.org.uk and fndaction.org.uk and from health professional sources such as neurosymbols.org and the MyFND app.



FND Hope

[Fndhope.org.uk](https://fndhope.org.uk)

FND Action

[Fndaction.org.uk](https://fndaction.org.uk)

Neurosymbols FND guide

[Neurosymbols.org](https://neurosymbols.org)

App store

[MyFND app](#)

Useful resources and links

Long COVID Physio
bit.ly/3wp3T8C

Absent Uk
bit.ly/3wrjQLu

British Heart Foundation
bit.ly/354ttVd

Nature Doc Clinic
bit.ly/3lySPlz

Action for ME
bit.ly/3N7CdLr

FND Hope UK
bit.ly/3JDcPuW

The Children's Trust
bit.ly/3L5OoX3

Section 03

SUPPORT FOR CHILDREN & YOUNG PEOPLE



What is Long Covid in children and young people?

Most children who get Covid-19 recover well.

Long Covid is a name for the symptoms that carry on for more than four weeks after someone catches COVID-19. It is a description made by the people who are living with Long Covid to help explain the difference between acute COVID-19 and prolonged symptoms. It is also used in many scientific publications to describe the prolonged health effects of Covid-19.

Both children and grown-ups can experience long-lasting symptoms. We aren't sure why some children experience them and others don't. This is one of the things doctors and scientists are working on right now.

Lots of different symptoms make up Long Covid and they can come and go. Sometimes symptoms can impact everyday life, making it tricky to take part in usual activities, school and to play with friends. Other times you may feel like your old self for a while, before getting symptoms again. This pattern of symptoms can happen for many months. It can be less months for some children and more months for others. The doctors who are caring for children with Long Covid tell us that children usually get better.

Feeling unwell for a long time can cause worry. It helps to talk. There are lots of people who can offer support. These can include family, school staff, friends and people who work in healthcare. Talking to people who are a similar age to you, or who have had a similar experience to you can be helpful. Lots of children have told our team that they enjoy the free online sessions we offer.

“

Take every day as a step forward, do what you can and if its a bad day, there is always tomorrow.

Tilly

“

There is always someone there for you. Don't give up and believe in yourself.

Emily



Get chatting! ChatBox is an online space for kids living with Long Covid. Kids between the ages of 8-17 years can chat online, be kids, and support each other. There is a different space for each age group to connect with other kids who are in the same age group and who maybe going through a similar experience. It is a great way to make new friends who 'get it'.
Sign up here: bit.ly/3ugaDCT

Support at home



Parents/Caregivers

These are the people who spend most time with you and who will probably be trying to make sure you get the support you need. When people can't see what is going on inside someone's mind or body it can cause them to worry. It can also cause disagreements: they might think you can do what you did before. As much as possible, try to share with them how you are feeling and what you want – do tell them when there is something you don't want to happen too.

Sometimes you might feel tempted not to tell them what you are thinking or feeling for fear that you will upset them or make them worry – generally they will want to know and will be worried if you don't say anything. They can be the best person to represent you – but only when they know what you want and need.

Parents or caregivers might have been ill with COVID-19 at the same time as you and they might have Long Covid too, in which case they will have some awareness of what you are going through. They might need to get other people to come and help out at home if they are not able to do everything they usually do.



Brothers and Sisters (siblings)

One or more of your siblings might have Long Covid; if they don't, they might find it difficult to understand that you are unwell, especially if symptoms are invisible. They might initially expect you to be how you were before and play together like you used to.

If you are unwell, siblings can sometimes feel a bit jealous by the attention that you are getting so they can say or do things that might feel upsetting. They are likely to be worried about you too, perhaps not understanding what is happening. They will need love and attention from your caregivers too.

As with parents and caregivers make sure you talk to your brother or sister about how you are feeling and tell them what you need. Find fun things that you can still do together.

Support at school

SENDco

The Special Educational Needs and Disabilities Coordinator in schools is a good person to oversee the changes (called reasonable adjustments) that you might need to be made to help you get back to, or stay in school.

Class Teacher

Your class teacher should know about the adjustments that are in place and make sure that these are put in place in every lesson. If you are struggling with symptoms do make sure to let them know so that they can help you.

Pastoral Worker/Counsellor/Emotional Literacy Support Assistant

If you are feeling sad, anxious or have any worries that you can't talk to your teacher about, you can reach out to a school pastoral worker or counsellor for support if your school has one. They can help you to explore your thoughts and feelings and also come up with practical ways to make changes that will help.

Educational Psychologist

Schools might also have an Educational Psychologist who specialises in supporting children with complex needs. They can work with you, your parents/carers and school staff to help make school better for you. They can support you with your learning, make a plan to support you with your friendships and help you if you are feeling worried, unhappy or angry.

School Nurse

A school nurse can provide a full assessment of all your health needs, and can refer to other



professionals to assess what you might need at school. They might also be able to support you to develop the skills you need to access healthcare on your own.

Friends

Friendships can sometimes be similar to sibling relationships so have a look at that section too. Letting friends know what you need help with or what you are finding difficult can be hard, but if you do they might offer you help and support that you find useful. Make sure to still talk to your friends about all the things you both like and take time to ask about them too. Sometimes they don't know what to say to make things better, so letting them know what they can talk to you about means that they know what might make you upset, or what you want to focus on instead of your health condition.

If friends or other students are being unkind, or bullying you about Long Covid, don't be afraid to talk to a teacher. Sometimes explaining to them what is going on and why you are being treated differently will help them understand. You do have the right for any private medical information to be kept private so think about what you would be happy for a teacher to share.

Support from health & social care

In healthcare you might end up seeing lots of different people, either at a Long Covid clinic or in different services. It can be difficult to know what each person does so here is a brief guide to help. Hopefully all of these people work together to support you in the best way possible.

General Practitioner (GP)/Paediatrician

A GP, also referred to as a family doctor, treats all common medical conditions. A Paediatrician is a doctor who has specialist training in medical care for children. When you have problems with your health, your GP is usually the first person you go to. They can assess what is going on for you, help with treating some of the symptoms you have with medication and arrange referrals to other doctors or healthcare professionals that can help if needed. Often, when children have lots of different symptoms and difficulties a GP will refer you to a Paediatrician. They can spend more time with you and will oversee your care. The Paediatrician will also be responsible for coordinating specialist services from other professionals. It is your GP who would refer you to a Long Covid Hub and to do so they might need to do some blood tests and a test for your heart (called an ECG).

Specialist Doctors and Nurses

Some doctors specialise in certain body systems. If someone has lots of different symptoms they might end up seeing several different doctors or specialist nurses. They usually assess with questions, observation and special tests to help rule out conditions and work out exactly what is happening.

Because Long Covid is a new condition it is not unusual for lots of the tests to come back normal. Research is happening all the time so working out which tests are the right ones, finding out what is wrong and how to manage ongoing symptoms is emerging.

Some specialists that you might see are:

- **Cardiologists** who specialise in the heart and blood vessels
- **Neurologists** who specialise in the brain, spinal cord and nerves
- **Respiratory specialists** who specialise in the lungs and respiratory system
- **ENT doctors** who specialise in assessment, diagnosis and treatment of problems with the ear nose and throat
- **Opticians and Orthoptists** who specialise in the care of the eye and visual system
- **Haematologists** are specialist doctors who treat conditions that affect the blood and the organs that make the blood
- **Immunologists** (also known as allergists) are specialists who assess, diagnose and treat health issues brought about by immune system problems
- **Orthopaedic specialists and Rheumatologists** who specialise in muscles, joints, connective tissue and disorders associated with these
- **Endocrinologists** who specialise in assessing, diagnosing and treating issues related to problems with hormones
- **Psychiatrists** who are qualified doctors who specialise in mental health.

Occupational Therapist (OT)

Occupational Therapists can work in lots of different places – in the hospital, in social services, in wheelchair services, in school, in your home or in CAMHS (Child and Adolescent Mental Health Services).

OTs focus on something they call occupations – activities that you do every day. They can come up with practical support, ideas, equipment and strategies to help you do the things you need to and want to do. Anything from brushing your teeth, going to the toilet, to going to school or taking part in hobbies. One of the things that OTs can help you learn is about how to pace yourself so that you can make best use of your energy. Your OT should understand Post Exertional Symptom Exacerbation and be able to explain how this may affect your recovery. They might also help you with your cognition – thinking, concentrating and remembering. They might also talk to the school about how to support you there.

Physiotherapist (PT)

Physiotherapy helps restore movement and function when someone is affected by injury, illness or disability. PTs consider the body as a whole as opposed to treating conditions and diseases. They can work in many settings and, like doctors and nurses, there are specialist PTs for most body systems. A respiratory PT will have expert knowledge in the lungs and associated diseases. A neurology PT will have expert knowledge in the brain, nervous system and associated diseases. There are also mental health and pain specialist PTs. Your PT will ensure you see the right one for you.



PTs help people through movement, exercise, manual therapy, education and advice. You might find that your Long Covid has made it difficult to sit, stand, walk or move parts of your body. PTs use detailed assessments and can order specific tests if necessary to diagnose why this is happening. Having identified any underlying causes and contributory factors, PTs use specialist skills to facilitate restoration normal movement and function.

Your PT should understand Post Exertional Symptom Exacerbation and be able to explain how this may affect your recovery. With that knowledge your PT should also be able to help you pace your treatment and identify when you should stop, see a doctor or another specialist. Ultimately, you will work with your PT as a team to identify and achieve your own goals. You should therefore be able to talk to your PT and agree on the right level of exercise for you.

Support from health & social care continued

Speech and Language Therapist (SALT)

If you have had any difficulties with your voice as a result of your Long Covid, or find it difficult to swallow food or drink, a Speech and Language Therapist can help. They can talk to you about foods and drinks that are easier to swallow or give you exercises to work on your swallow or speech. They can also work on: difficulties in understanding language (this may relate to attention, auditory issues, processing); difficulties in producing language (e.g. speech, finding words, putting sentences together) or difficulties in using language appropriately. They will help you with your oral (vocal) and written communication or help you learn alternative ways to communicate if that is needed.

Pharmacist

Pharmacists, also known as Chemists, have specialist knowledge in medicines and health. They are experts at answering questions on medicines. You will find them attached to GP surgeries, hospitals and some well known highstreet shops. They can support you to make sure you are taking the right medication, at the right times and can talk to you about how to best manage any side effects. They can make sure that the medications that you are given by different doctors don't interact or make each other ineffective. You can also talk to them about any non-prescription medicines you take to make sure they are safe. If you find it difficult to take tablets they might also be able to suggest alternative ways to take any medication you have been prescribed.



Dietician/Nutritionist

If your Long Covid has affected your smell, taste, you have found it difficult to eat or have developed new allergies to food, a Dietician or Nutritionist may be able to assist. They can help by working on smell and taste re-training, advise on a diet that might help or prescribe supplements to keep you healthy if you aren't able to get all the nutrients you need from food.

CAMHS/Psychologist/Counsellor/EWMHS

CAMHS stands for Child and Adolescent Mental Health Services. EWMHS means Emotional Wellbeing and Mental Health Services. When you are very unwell physically you might find that this impacts on your mental health. As a result you might start feeling depressed or have anxiety and it can be useful to be able to address this because our minds and bodies are so interlinked. Some children with Long Covid have developed something called PANS (Paediatric Acute-onset Psychiatric Syndrome) and might be experiencing things like Tics, Obsessive Compulsive Disorder, Food restriction, Hallucinations, Aggression and Sleep Problems). Although, if identified early enough this can be treated, some of the symptoms might last longer and you might need support to help manage them.

Some children or young people with Long Covid have had thoughts of self-harm or suicide. If this has happened to you, please know that this can happen to anyone and please speak to a trusted adult who can help you seek support.



Speaking to a Psychologist or Counsellor in confidence about anything that is making you feel sad or anxious can be useful because they are not linked to you. There are also phone, text or online chat services that you can use anonymously if you need. See **page 56** for useful resources and links.

Social Worker (SW)

If you or your parents/caregivers need help at home, or if you are having difficulties going to school, you might see a Social Worker who will talk to you about what support you need and help arrange it. They will be focused on making sure you get all you need to develop and, if you are older, might help with supporting you to become more independent.

How to help yourself

It can sometimes feel that some things are scary and out of your control and of course that is true of some things.

However there are things that you can do to support yourself and here are some of them.



KEEP SPEAKING UP

Try to explain what you think and how you feel. It will help parents and caregivers understand more about what you need.

Keep telling people what you are thinking and how you are feeling, and what you want and need until you get support. Ask a trusted adult to help you if you need it.

Keep telling your truth.



FOCUS ON HEALTHY LIVING

Try to get good sleep and eat and drink as well as you can. Where you are able to, keep doing the things you love, or find new things to try that you might love as much.

Your body can be quite clever at letting you know how it is feeling. Listen to how your body feels and try to give it what it needs.



FOCUS ON THE LITTLE THINGS

It might not be possible to feel positive all the time, and that is okay. Thinking about the little things that make you smile can be helpful. Try to book things into your day so that you have something to look forward to but be flexible about when and how you do them. Make a note of the little things that make you feel positive at the end of each day.

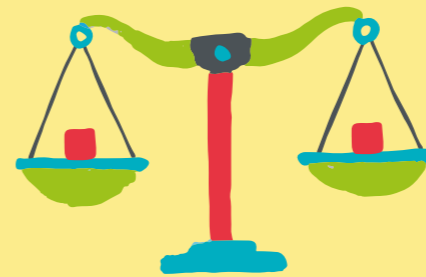


KNOW THAT IT IS OKAY TO NOT BE OKAY

What is happening to you can feel overwhelming. It's okay to cry, feel worried or angry but if these emotions become too difficult to deal with, know that there are people who will want to help you manage these feelings. Share how you feel with a trusted adult. There are some useful links to mental health and wellbeing organisations on **page 56**.



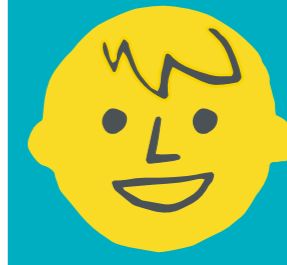
Childline
bit.ly/3qruDS1
LCK Support Services
bit.ly/3ubnDd3



REST AND PACE, LISTEN TO YOUR MIND AND BODY

Rest is a friend to anyone living with Long Covid. Learning to pace yourself to best use your available energy is one of the most important things you can do to help support recovery. We know it's not always easy. Try to listen to when your mind or body is telling you it is tired and stop to rest if this is the case. Like any new skill, pacing is a skill to be learnt. It is likely that you will make mistakes and that's okay. One of the most challenging things to learn is to rest before your mind or body tells you it is tired. This can be especially important if you have something called Post Exertional Symptom Exacerbation (see **page 36**) which can be a symptom of Long Covid.

See the LCK **Cautious Tortoise** and **Pacing Penguins** in the Resources Section for more detailed information on how to pace effectively.



LAUGH

The saying goes that laughter is the best medicine and there's some truth in that. It's okay to be happy and have ongoing symptoms at the same time. These will often feel like 'good' days. Where you can find time to play and be silly and have a good belly laugh. When this isn't possible, it might help to remember back to a time when you felt like this.



KEEP A DIARY

This can be a useful tool to write down your thoughts and feelings but also Your activities and the symptoms that you get. Using a diary can help you to notice patterns, triggers and things that help you to feel better. This can all help you work out how to best pace yourself too. A symptom tracking app is useful.

Some things children & young people ask...

What if my experience hasn't been positive?

We are here to help support you. Some children say they have found it difficult to get support from people they thought would help them. Sadly this is especially true of doctors and healthcare Professionals up until now. Long Covid Kids, are really sorry that this has happened.

The last two years have been difficult for many people. Everyone is still learning about Long Covid while they are also trying to help the people living with it. For a variety of reasons some healthcare professionals may not be up-to-date with new research. You have the right to be treated with respect and to be heard.

The Long Covid Kids team are trying to help improve the experience for children by getting the right messages out there. Knowledge and understanding of Long Covid is growing every day through research and practice. We really hope that these changes mean that more children are having a positive experience.

Each time you meet a new doctor or healthcare professional try to give them a chance to prove they can support you.

Make sure you let them know how you are feeling. If there is anything that you feel unsure about try to explain it to them. Talk to your trusted adult. If you still don't feel heard, please talk to us. You can **email us**, or speak to one of our experienced moderators in ChatBox to ask for support.

Well-informed doctors and healthcare professionals who read the latest research on Long Covid will be happy to listen to you. They will be happy for you to direct them to resources that help them to support people like you living with Long Covid.

If you are really unhappy with the way you are treated, and it doesn't make you feel supported, your family can ask for a second opinion. You do have the right to complain if you are concerned that the care you have received has not been good enough.



NHS PALS (Patient Advice and Liaison Service)
bit.ly/3NllggG

What if my family does not believe in Long Covid?

Talk to your family about how you are feeling. Try to explain how your symptoms affect you.

You may find it helpful to show them these resources to help them understand more about Long Covid.

Consider reaching out to a trusted adult from your extended family (e.g Aunt, Grandparent) or somebody at school. They might be able to help speak to your family for you or with you.

Depending on your age you have different rights to seek support without consent and whether or not this support has to be kept private or confidential.

You could phone your GP to seek support and they will assess whether you have the capacity to do this.

Can I consent to my own treatment?

People aged 16 or over are entitled to consent to their own treatment. This can only be overruled in exceptional circumstances. If you are under the age of 16 you can consent to your own treatment if you're believed to have enough intelligence, and competence to fully understand what's involved in your treatment. This is known as being Gillick competent.

Can I refuse to have treatment?

If you refuse treatment, which could cause you serious harm, your decision can be overruled by the Court of Protection. This is the legal body that oversees the operation of the Mental Capacity Act (2005). If you have refused treatment your parents may consent for you, but it's usually thought best to go through the courts in this situation.

Do I have a right to keep my treatment confidential?

Yes. Article 16 of the UN Convention states that children have a right to privacy. This means that you

are entitled to respect for privacy and confidentiality, for example, in getting advice and counselling on health matters, depending on your age and understanding. Breaking confidentiality is done only when it is in the best interest of you or the public, required by law or if you give your consent.

Useful resources and links

Kooth

www.kooth.com

Available as an app or on a desktop, Kooth is for CPY age 10–25 and is free, safe, anonymous support accredited by BACP.

The Mix

www.themix.org.uk

0808 808 4494 (3pm–12am daily)

Various avenues of support such as live chat, discussion boards and helpline for CYP age 10–25.

Young Minds Textline

Text YM to 85258 (free from EE, O2, Vodafone, 3, Virgin Mobile, BT Mobile, GiffGaff, Tesco Mobile and Telecom Plus).

Provides free, 24/7 text support for young people across the UK experiencing a mental health crisis. All texts are answered by trained volunteers, with support from experienced clinical supervisors.

Young Minds Website

www.youngminds.org.uk

This is a great website that a child or young person can access with excellent resources. Parents can also access it for ways to help support their child.

The Emotional Wellbeing and Mental Health Service (EWMHS)

bit.ly/3isycTv

Provides advice and support to children, young people and families who are in need of support with their emotional wellbeing or mental health difficulties.

SUPPORT FOR PARENTS & CAREGIVERS



Support for parents & caregivers

Include links to the FaceBook group?

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LCK has been a complete lifeline. Thanks to LCK and shared information, my son got actual help, rather than a few vague word salads about dysregulation and a lot of minimising and gas-lighting.

Parent & LCK member

“

All the while children are suffering harm from SARS-CoV-2 infection, Long Covid Kids will be here for them. Nobody is alone. And because we comprise of all known and new conditions that arise from SARS-CoV-2 infection we have real-time opportunities to further existing knowledge, understanding and ultimately treatment for the benefit of them all.

Nathalie Pearson
Founding Member and COO

Stages of COVID-19

The National Institute of Clinical Excellence (NICE) produced a rapid guideline (download below) which identifies three separate stages of SARS-CoV-2 infection.

Stage 1: Acute COVID-19

Signs and symptoms of COVID-19 for up to four weeks.

Stage 2: Ongoing symptomatic COVID-19

Signs and symptoms of COVID-19 from four weeks up to 12 weeks. This is where the patient-made 'Long Covid' term fits in that tends to describe the signs and symptoms that develop after stage 1. This is also the stage during which the COVID-19 complication PIMS-TS commonly arises.

Stage 3: Post-COVID-19 syndrome

Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed. (12 weeks or more).

Long COVID Physio have produced a short video helpfully explaining what Long Covid is. Long Covid is a diagnosis of exclusion – that means – and this is good practice – that other conditions that could be causing the symptoms should first be excluded. NICE say. **“To effectively diagnose, treat and manage a condition it needs to be defined and distinguished from other conditions.”**



Long COVID Physio
bit.ly/3wp3T8C

As a result, you might find your child gets lots of different words and labels and names applied to what is going on with them – and sometimes Long Covid (or one of its other terms) might get added eventually if there are still some symptoms that remain unexplained.

None of this means that Long Covid isn't a real condition and experience – it just shows that we are all still getting to grips with exactly what it is. In the future there might be biomarkers that can be identified using blood tests or other investigations – but we aren't quite there yet.



NICE guideline: COVID-19 rapid guideline: managing the long-term effects of COVID-19

This is a living guideline and is added to as new evidence emerges, last updated in November 2021. It covers identifying, assessing and managing the long-term effects of COVID-19 and makes recommendations about care in all healthcare settings for adults, children and young people who have new or ongoing symptoms 4 weeks or more after the start of acute COVID-19.





First steps

How do I spot Long Covid?

Remember that many children recover well after infection. As with many post viral illnesses it is not unusual to feel unwell for many weeks yet make a full recovery. Some children take longer to recover than others, but may not develop Long Covid.

New persisting and/or fluctuating symptoms that continue for four weeks or more, especially when part of a constellation of symptoms, require medical assessment. **Think Long Covid.** It may take years to understand Long Covid and define the list of paediatric symptoms.

See **pages 22–23** for the full list of symptoms.

Points to remember:

- Some children can appear to get better after their initial infection then develop symptoms weeks or months later.
- Long Covid has a relapsing and remitting nature where symptoms can get better and then worse again.
- Symptoms can present individually, but are more often in clusters.
- The severity of the symptoms can change throughout the day, week and duration of illness.
- New symptoms can develop at any time, and medical advice should be sought if this occurs.
- Children with ongoing symptoms after infection (Long Covid) can develop or be diagnosed with other known illnesses. There may be treatment available for these so it is important to seek medical advice.

By continuing to take your child to the doctor we can help doctors learn about Long Covid and evidence the impact of ongoing symptoms.

Refer to the mechanisms for Long Covid on **page 16** to understand how Long Covid can present.

What should I do if I suspect my child has Long Covid?

Take a deep breath.

Remember that each child's recovery experience is unique and that doctors report that many children they see do recover well.

You are not alone.

Join our **Long Covid Kids Support Group** for peer to peer support. There are lots of ways you can support your child. Referrals can take time. It is advisable to reach out for support early.

Knowledge is power.

Understanding what we know about Long Covid so far can be helpful when trying to navigate services and manage symptoms. It may improve the recovery pathway for your child.

How can I help my child get better?

Using the unique combination of lived and professional experience, Long Covid Kids developed **Cautious Tortoise** and **Pacing Penguins**. Two useful and practical resources to guide recovery and manage energy limitations.

The resources are based on well-documented evidence from a number of different conditions where people also have fatigue/energy limitation as a symptom, such as Stroke, Cancer, Heart Disease, Multiple Sclerosis and ME/CFS. Some elements of energy limitation might be similar across these conditions and others might be different.

Unpicking what causes fatigue can be very tricky and it is often a combination of factors all adding up together.

Until we know the mechanisms in the body that cause fatigue we have to use the principle of **First, Do No Harm***.

Pacing is generally thought to be one relatively safe way to manage energy limitation. It doesn't prohibit movement. It doesn't prescribe exercise.

Some top tips to help recovery are:

Accessing healthcare: The right healthcare at the right time – this is likely to be an ongoing process – especially as we learn more about Long Covid.

Focus on things you can control: Lifestyle factors, sleeping well, good nutrition (including supplemented nutrition when necessary – seek specialist advice) and maintaining good levels of hydration

Reducing stress: Allowing convalescence, keeping routine, structure and boundaries to look after mental as well as physical health.

Validation: See 'When words run out'. **Page 70.**

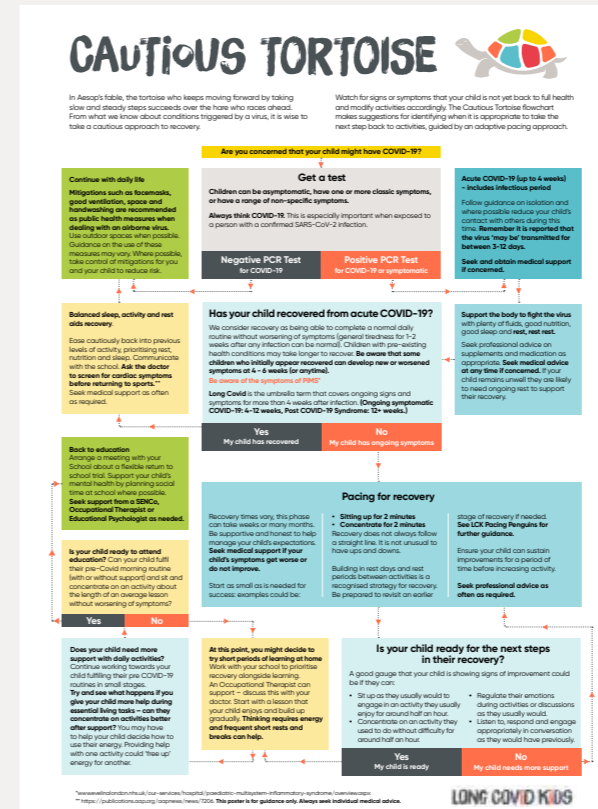
Asking for and accepting help: Maintain open communication with everyone involved.

Self-care: You need to look after you too. Nobody can pour from an empty cup.

Rest and pacing: Please see our guides **Cautious Tortoise** bit.ly/3CWsXFd **Pacing Penguins** bit.ly/3qk7H7e

Foster hope: Occupational balance between activities that your child wants to do, needs to do and things that are good for their health – feed the mind and body with love, light and laughter. See **page 86.**

Move towards acceptance: This will be a cyclical process but as much as possible aim to live in the present and try and reduce worry about the past or future. See **page 72.**



Download our Cautious Tortoise poster for a step-by-step guide to supporting children and young people who are recovering from COVID 19. bit.ly/3CWsXFd

Cautious Tortoise

Cautious Tortoise was made by people living with Long Covid, for children and families living with Long Covid. It provides a practical step-by-step guide to supporting children who are recovering from COVID-19. It can be used by adults too.

The advice in this guide may reduce the potential impact of Long Covid. We don't yet have the longitudinal data or conclusive research that some clinicians would like to see before supporting this guide. However, the Long Covid conundrum is worldwide. We must learn from other post viral conditions and the weight of worldwide observational evidence including that which we have from our members. Our guide is supported by Long COVID Physio and Occupational Therapists For Long Covid.

Steps include:

- Provide every opportunity to allow plenty of rest and sleep.
- Seek medical support as often as you feel you need to, especially for new or worsening symptoms.
- Encourage fluids and good nutrition.
- Ask the question, "Is the child ready to do this?" at each step back to 'usual' life.
- Maintain open communication with your child, with school and with healthcare professionals.
- Remember recovery isn't linear – don't be afraid to take a step back at anytime if needed.
- Encourage slow, gradual and sustained changes.
- Pace activities and manage energy levels to support recovery.

Accessing healthcare

Your General Practitioner (GP)

The GP will generally be the first point of contact for any ongoing concerns about your child's health. The GP is able to support the process for a diagnosis and make referrals for coordinating services to provide treatment and support.

GPs have the ability to refer any child with ongoing and persisting symptoms lasting four weeks or more to the Long Covid Hub or to additional support if their symptoms have lasted for more than four weeks. It may be helpful to refer them to additional information for example, **Long Covid Kids**

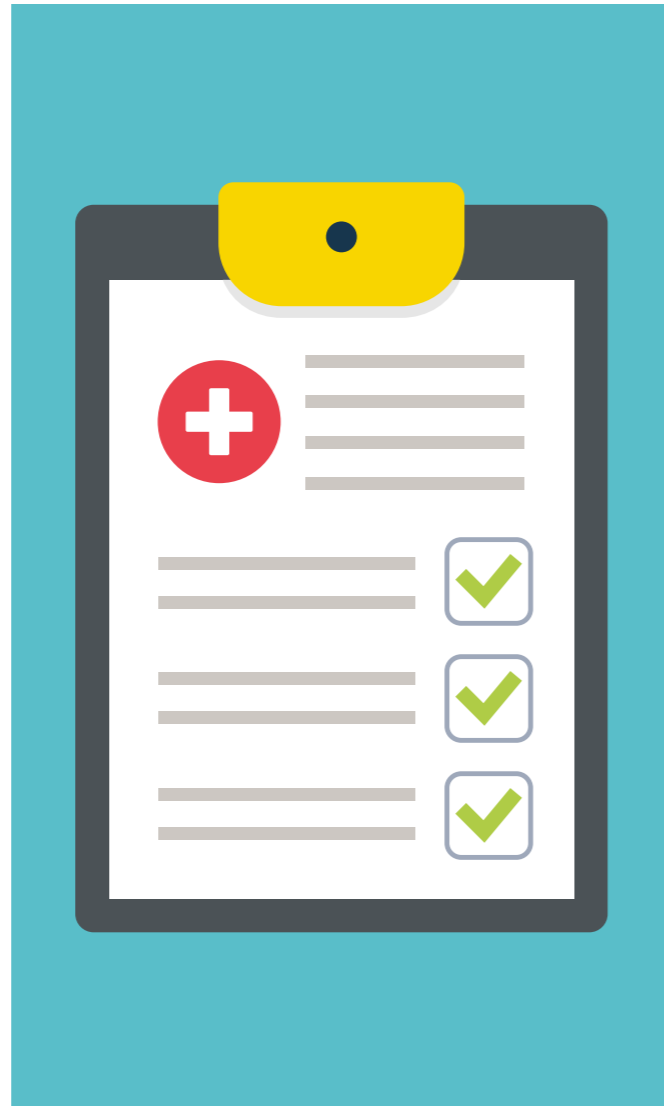
The GP can also refer to a Paediatrician who may in turn refer to other specialists who may be able to offer support.

If your child can't be seen in a Hub because they are based in a country without one, the Paediatrician or GP should be able to coordinate any referrals or investigations that are needed.

Long Covid Kids often receive reports from parents who have found it challenging to access the support services their child needs. We continue to represent children and young people living with Long Covid in expert forums, research panels, health organisations and parliamentary groups to ensure things improve. [Find out how you can support our work.](#)

Preparing for a medical appointment

Keeping a record of symptoms and anything that you have noticed that helps your child provides key information that may assist



doctors and healthcare professionals to understand your child's experience. Medical appointments can be short – preparing for appointments can help ensure you make the most of the time that you are allocated.

Recalling the patterns and severity of the fluctuating symptoms of Long Covid can be challenging, especially if there has been a long wait for a specialist appointment. Using the **PeopleWith app** is a helpful way to document symptoms. Long Covid Kids have been working with PeopleWith to help improve the understanding of Long Covid in children. You can choose to print off or email a summary of information for your doctor or yourself.

See the resource [Helping you to get the best from your healthcare](#) on **page 134** for things you might find helpful to document. Add as much detail as possible as diagnosis is often based on history taking.

Multidisciplinary teams

Your child may need to see several different health and social care professionals. This is more effective when it is part of a Multidisciplinary Team approach because Long Covid is a new and complex condition that requires specialist clinical reasoning. Put simply, we all solve puzzles in different ways – the same is true for specialists. It may be necessary to repeat some information because different specialists might need to ask the same question for a different reason. We appreciate it can feel exhausting and frustrating. Try to use it as an opportunity to help health and social care professionals pick up on little clues that could move your child towards the support they need. One way to improve communications is to arrange a time to share a copy of your notes with the professionals involved. In complex cases it can be helpful to arrange two or more shorter meetings.

On **pages 46-51** we have included a (non-exhaustive list) of who could be involved in supporting care along with a brief guide to what they might be looking for or things they might do. As well as specialist doctors and nurses there are lots of other health professionals who can help. Ask your doctor about these services and others, especially if you find it harder to cope with day-to-day life at home or school.

Support is available.

Child and Adolescent Mental Health Services (CAMHS) can also help and sometimes they can provide family as well as individual therapy or counselling. See **page 56** for links to additional impartial counselling services that may help.



People with Health
bit.ly/36iDvTc

How to talk to children about Long Covid

The British Psychological Society in their paper, [Talking to children about illness.pdf](#) (bps.org.uk) states



Adults have a key role in helping children understand what is going on, providing information and reassurance, limiting media overload for children and being aware of how their own reactions might impact on children.

Every child is unique and so what you say and how you talk about Long Covid will vary depending upon the age, level of understanding and stage of development of the child. However, as with any tricky conversation, you may want to consider the following:

Choose a time that is right for you and your child.

Try to gauge when you think they are 'in the mood' for a chat and are not too tired. Avoid times of day when their symptoms are worse, after a tiring activity such as attending school or when they are doing something else. You also want to ensure that you have enough time available to give your undivided attention; to listen, talk, answer questions or simply to spend time with your child.

Pick a quiet space where the child is comfortable, relaxed and away from distractions.

Find out what they already know and what they would like to talk about.

Use clear language that is appropriate to their age, level of understanding and stage of development. Avoid abstract language or medical jargon that they might not understand.

Give them information in short chunks appropriate to their levels of understanding and attention; don't overwhelm them with too much information in one go.

Allow them to respond in their own way, to ask questions and to say how they feel. Younger children, children with communication difficulties or children with learning difficulties may have less vocabulary, find it harder to express themselves with words and may tend to express their feelings through their actions or behaviours. There are a wide range of emotions cards or emoji symbols readily available that children can use to express their feelings if they are unable to find the right words, **e.g. Emoji Check In - Bing**, or they might want to play, draw, paint or make a model to show how they are feeling.



Emoji how are you feeling chart shorturl.at/enwZ0

Answer questions honestly – it is ok to say that you don't know the answer to a question, e.g. "I don't know the answer to that yet, but there are many doctors who are trying to find out".

Help your child label and name their emotions by labelling and naming yours. Explain that how they are feeling is expected and understandable, e.g. "it's ok to feel like that".

Give the child time to process what they have heard. You may need to repeat the conversation or key points at another time, especially for a younger child.

Show that you have heard and value what they have told you, e.g. "thank you for telling me how you are feeling, I will do my best to help you". Involve them in planning their day, ask them what support would help them at school, or what you can do to help them at home e.g. "how can I help you with?", "is there anything you need from me?" or "would having help you?"

Reassure them that you are there for them and that you will support them with everything they need, e.g. "I am here for you and we are going to work through this together".

Encourage them to get additional support, e.g. from an adult at school, from peers, e.g. in **LCK Connected** or to search for any child-friendly Long Covid information.

Return to the conversation and check-in with the child at a later stage. Ask them how they feel now, they may have new questions, or be experiencing different feelings.



LCK Connected bit.ly/3u3z8TG

LCK Padlet for parents and families bit.ly/3qqa7Bg [not working?]

If they don't want to talk.

Reassure them that they can talk to you at another time, e.g. 'you can talk to me at another time, I'm always here for you'.

See whether they would like to talk to someone else instead. They may prefer to speak to someone slightly removed from the situation (such as a friend, a member of school staff or another family member), e.g. "if you want to talk to someone else, that's ok too".

Check whether they would prefer to express their feelings in another way. Depending on their age, this might be through play, by writing a letter, sending a text message, painting, drawing, making a model, etc., rather than by talking.

Just 'be' with your child if they don't want to talk. Don't be afraid to sit in silence; just being there, holding their hand and giving them your time will help them.



Consider using conversation starter prompts to give your conversation some structure. shorturl.at/qsuFV

When words run out...

Chronic illness is hard. Words matter. Here are some suggestions of positive phrases that can be used.

Start with 'I'

I enjoy your company

I'm looking forward to seeing what you do

I believe you

I am curious to know what you think

I couldn't have done that without you

I believe in you

I see you trying your best

I love you

I love you no matter what

I won't walk away

I'm glad that you are here

I'm proud of you

I'm happy to talk to you

I'm listening

I'm looking forward to seeing what you do

Start with 'You' or 'Your'

You have made me see things in a new way

You know your own body best

You make a difference to us

You make me smile

You make us a family

You can change your mind

You can ask for help

You are strong

You are more than your emotions

You are a good friend

You are kind

You are capable

You make a difference

You can be happy and sad at the same time

You are enough

You don't need to be able to do that.

Your words are powerful

Your ideas are important

Your body is yours

Start with 'We'

We are learning together

We all make mistakes

Other ideas

Let's figure this out

Let's keep a diary

It's okay that you are finding this hard

It's okay to cry if you are sad

It's fun to do things with you

What else could this be?

If something doesn't feel right, let's talk

What do you feel grateful for today

The world is better with you in it

Tomorrow is a new day

Thank you for helping me

All people deserve good health



YOU MAKE ME SMILE



YOU ARE STRONG



TOMORROW IS A NEW DAY



YOU MAKE A DIFFERENCE



I LOVE YOU NO MATTER WHAT.

Managing emotions

Originally a blog post by Rox Talbot,
OT Student, University of Northampton
On Grief and Moving Toward Acceptance

Having a diagnosis of a relatively new and poorly understood condition can raise difficult emotions akin to grief. Kubler-Ross (1969) identified the process of grief as staged through denial, anger, bargaining, depression, and acceptance. It is important to remember that moving through this cycle will not be a linear process and just as you think you are coming to terms with one aspect, your emotions can flit right back to the beginning of the cycle or you may even skip sections of the cycle.

When my son was diagnosed with additional needs, I skipped straight to acceptance because it was something we had suspected for many years and I suddenly felt validated. However, at times I skip back to anger when things are not progressing as they should, or he is not being supported as much as he needs. During these times I grieve for where he should be, but then I go straight back to accepting that he is who he is. I do this through my own internal dialogue as well as discussing issues with other parents who I know are

going through similar situations and who are also experiencing the same cycle. Not everyone's experience will be the same, however parallels can be drawn and reflected upon.

Denial

No parent wishes for their child to be chronically ill and so it is a normal reaction to reject that idea and search for every possible cure. However, it is important to remember that a diagnosis is not the be all and end all outcome, but often purely a label through which access to other services may be gained.

A cure may not be possible (in Long Covid at least not until more research is completed) but we can always take steps to manage the impact that the condition and its symptoms have on your child.

Anger

It is natural to feel angry and to question Why? Why me? Why my child? Why now? What did I do wrong? In these situations, talking to families who are going through a similar journey can be really helpful. You can find a link on the support available

with Long Covid Kids here. Talk to your family, your friends, peers or even a trained counsellor for additional support.

You are just as entitled to support as your child is. It is ok to ask for help.

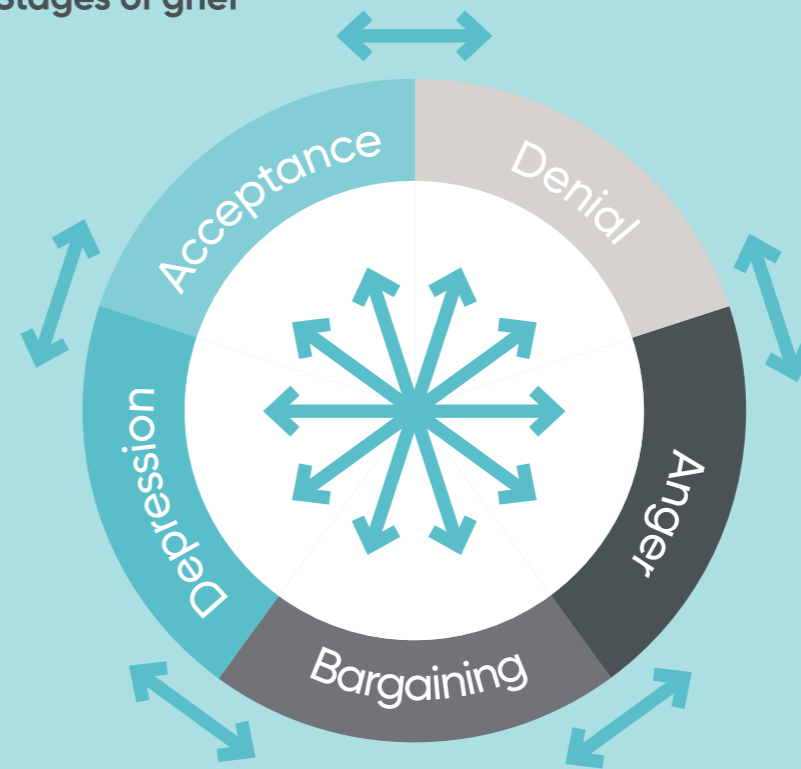
Bargaining

Also known as negotiation, this is an attempt to regain control of the situation. "What can I do to change this?", is a question often asked, and the answer may be nothing. What if I hadn't caught Covid? What if I had asked for a second opinion? What if I hadn't sent my child to school? If you are a spiritual person, you may find yourself praying and interacting with your higher power to substitute your child's illness for a sacrifice of your own. This process is part of the acceptance that there is nothing differently that could have been done and once this is psychologically accepted, the next stage may be depression.

Depression

In this stage, parents can find themselves depressed at

Stages of grief



seeing that their child has ongoing challenges. Feelings of guilt, anxiety and hopelessness can follow as well as a realisation of the emotional/financial/physical demands that are placed on you. Again, it is important to acknowledge these feelings and seek advice on how to further deal with this stage.

Although depression can be an entirely appropriate and necessary response, if it continues or increases in severity it can also become a clinical diagnosis. If you are concerned, do speak to your doctor who can help you to access support.

Acceptance

Next, we come to acceptance. We realise that having a child that needs extra support is okay. We still love them

unconditionally and we are going to work as a team to try and achieve what is important to the child and improve their quality of life in line with what they are able to and want to achieve. Acceptance is about coping with a new reality and embracing the present, it doesn't seek to ignore the loss.

The World Health Organisation (1948) defined health as **"a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity"**. By this definition, children with Long Covid can indeed be healthy as long as this wellbeing is maintained. Wellbeing is defined by the Cambridge Dictionary as the state of feeling healthy and happy. The significance of this

definition is the word 'feeling'. We can still feel healthy when our physical or mental health is affected and so the state of wellbeing is entirely dependent on the individual's perception of their own health and happiness rather than a professional judgement.

With this in mind, it can be helpful to focus on your child and the impact their condition has on their (and your) daily life rather than the overall label of Long Covid as an illness/disability.

It is also worth recognising how others around you, including your child, siblings or other family members are experiencing this process too.

Padlet boards

Find out more information on our padlet boards



For Children
www.padlet.com/LongCovidKids/Children

For Young People -
www.padlet.com/LongCovidKids/YoungPeople

For Parents and Families
bit.ly/3qqa7Bg

Research: media & facts

Long Covid is a new condition and Long Covid research is being published at speed. It can be difficult keeping up-to-date with research and we often rely on newspapers and other media to share the findings more widely. Some of these sources share the information in a way that is designed to evidence a specific agenda.

Long Covid Kids have expert Champions that we look to for accurate analysis of research. Our Data Analyst and Champions report accurate and unbiased information that you can trust – if this is an area you would like to know more about see our blog for **10 Questions to Ask when Reading Research Papers**.

Questions to ask to come to a safe conclusion about treatments

What is the person's/organisation's intention in sharing this potential treatment?

- To offer help and support?
- To share something that worked for them?
- To sell you something?
- To make a name for themselves?
- Is the recommendation within the scope of practice of the person recommending it or carrying it out? What are their qualifications/experience?

Use trusted sources of impartial information (such as the NHS, CDC or ECDC) to read up on the treatment you are considering so that you understand the evidence for it, the conditions it has been shown to be effective for and the benefits, risks and/or harms you need to be aware of.

How easy is it to understand what they are offering?

- Can they explain it to you in easy terms?
- Is their explanation clear and logical?
- Are any costs clear and mentioned upfront?
- Do they say how often you might need the relevant support/treatment? Or how long you might need to do it/take it for before you see improvement? Some things might be effective but only in very specific circumstances or if given enough time – is this made clear?

Your research will also help you and your child know what will be involved in the treatment before attending.

What supporting information is available to evidence the recommendation?

People often recommend taking, or doing something for a new condition because it worked for another one. Long Covid is a new condition and to date there is very little, if any, quality research for treating children living with Long Covid.

How closely does your experience match?

What works for one person won't always work for someone else. The age, gender, ethnicity, sexuality and culture of a child may lead to them having different needs. Some people also have pre-existing health conditions or disabilities that could mean their needs will vary.

Are the risks of doing what is offered made clear?

Do you know whether there are any risks of harm or side effects, and are you given clear steps on what to do if this happens.

Can you ask questions if you are unclear about something? How well are your questions received? Does what is being offered sound too good to be true?

- It is important that, if you don't feel comfortable about a treatment being offered, you are able to ask about the evidence or guidance that supports it and challenge it with new evidence that you are aware of. Practitioners should respect your opinions and seek to understand and address any concerns you may have. In the NHS you can also ask for a second opinion but this is not an automatic right.
- Beware of anyone asserting that they are 100% certain that X is what is causing the problem or that Y will cure it. If that was the case and it was cost effective, it would be likely that this treatment would already be more readily available.

Deciding to go ahead with treatment

If you can be sure you will do no harm by trying something, even if it doesn't have a lot of evidence to support it, you might decide to go ahead. However nothing is without risk. Set realistic expectations of success so that you aren't disappointed if something doesn't work, or if it doesn't work as well or as quickly as you hope for.

Make sure to document your child's baseline/current signs/symptoms and function and document any changes that occur so that you can objectively see if it has made changes or been effective. Be cautious about trying lots of different things all at once. It can then be difficult to work out what has had benefit and what has not.

Ideally, we would also recommend that you inform your healthcare provider about your decision to go ahead with any treatments, especially if there is any risk of interactions between treatments that they might offer.

NHS treatment

Changing practice in the NHS does also take time. The main guidance used by the NHS is published by The National Institute for Clinical Excellence in Health (NICE). This is guidance and not law, but provides clinicians with evidence-based recommendations developed by independent committees, including professionals and lay members and consulted on by stakeholders such as patient groups and professional bodies. Individual organisations are responsible for implementing the guidance and may be called on to identify why they haven't been able to do so if asked.

Being aware of the relevant guidance for the condition your child is experiencing can help you negotiate treatment and management options. However, it can take months or years for guidance to become embedded in practice, not least because sometimes that guidance relies on higher staffing levels, staff training or equipment provision – all of which takes time to implement.



10 Questions to Ask when Reading Research
[url here](#)

Support for you and your family

Friends and family

There has been inconsistent and poor governmental, public and media messaging about COVID-19 and Long Covid. Not everyone will view things in the same way.

As much as possible it helps to have everyone 'singing from the same hymn sheet', so caregivers all saying and doing the same things, siblings showing understanding and support, wider friends and family knowing how and when to help and when to step back. This all comes down to communication.

Your child should be at the heart of that communication but the needs of the whole family are important too – and often need to be balanced. For this compromise is also necessary. Make sure to focus on self-care and to give time and attention to other siblings and significant others as well as your child living with Long Covid.

Make sure they have ways to keep connecting with friends – old ones and new ones. Some people find it really positive to connect with others with the same condition to learn from them and to know they aren't alone. But maybe your child has taken up a new hobby and wants to connect with others with the same interests.

Don't be afraid to stop seeing people who really aren't helpful and who cause unnecessary stress. This can be really hard to do, but you need to do what is best for you and your entire family.

Local Authority

Your local council has certain responsibilities for providing services in your local area. These can be to do with issues around education and housing amongst others.

If your child is considered to have a disability, there may be services, schemes, support and help they can provide. Social Services will do a needs assessment and arrange any social care services you need.



www.gov.uk/help-for-disabled-child

One of the services that can be provided to you as a caregiver is a carer's assessment – this looks at your needs for support and can include things like providing help at home, respite, support with work and planning for emergencies.

If you or your partner also have Long Covid and you have other children at home then they may be considered to be a Young Carer – you will also have a right for help and support with this role. See also Carer's Trust.



www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights/



Benefits

Living with a long-term disability or health condition can be costly and there are certain state benefits that might help with the cost of living. Benefits is a very complex and ever-changing area and so we will direct you to some specific sources for further information



Entitledto

This is a benefits calculator that assesses your eligibility for certain benefits.

www.entitledto.co.uk/

Citizen's Advice

A helpline and local offices help provide information and practical support in applying for benefits.

www.citizensadvice.org.uk/benefits/

A few relevant key benefits:

Disability Living Allowance for Children

A cost of living allowance that explores someone's care and mobility needs.

www.gov.uk/disability-living-allowance-children

Child Tax Credits/Working Tax Credits or Universal Credit

www.gov.uk/working-tax-credit

www.gov.uk/universal-credit

Carer's Allowance

Eligible if you care for someone 35 hours per week or more.

www.gov.uk/carers-allowance

Direct Payments

Help and services that you can choose and pay for yourself instead of through social services.

www.gov.uk/apply-direct-payments

Work & caring for a child with Long Covid

What can I expect from my employer?

Employees have certain rights that make provision for parents and caregivers to have time off for children in an emergency. Employers have to facilitate 'reasonable' time off to deal with the emergency. There is no limit to how many times you can have reasonable time off but if it is affecting your work your employer may want to discuss this with you.

Employers should be able to provide you with a copy of their policy about 'reasonable time off'.

Employers may ask you to use holiday/annual leave or unpaid parental leave when you need time off. Your employment rights are protected if this leave is granted.

Compassionate leave may be granted. This is at the discretion of the employer and will be outlined in your company handbook/policy.

How should I structure my work?

It may be possible to request flexible working arrangements such as working from home, part time, reducing your hours temporarily or permanently or by moving to an annualised hours contract. You must usually have worked for your employer for 26 weeks before asking for these flexible options. Employers need to deal with requests in a reasonable manner.

Both you and your partner can apply for flexible working or leave. It may be possible to organise a pattern of work that supports your caring responsibilities.

What happens if my employer is not supportive?

Unions: If you already belong to a union, contact your local or regional representative to support ongoing discussions with your employer.

ACAS is the Advisory, Conciliation and Arbitration Service – they can help with employment disputes. Anyone can use this service, including those who do not belong to a union. Should it become necessary to take an employer to a tribunal, you will need to apply through ACAS.

What if I'm asked to resign?

Do not resign. This may affect your right to claim benefits (see **page 77** for details on some benefits that might help if you are losing income). It is best to have open and honest communication with your employer and negotiate an outcome that works for all parties.

Where can I find more support?

Long Covid Work is a new organisation made up of professionals with lived experience of Long Covid who are working in partnership with Long Covid Support and others, such as the trade union congress and law centres, to try and look at how to support people with, and parents of children with Long Covid when it comes to work and employment.



www.longcovidwork.co.uk/



Support at school

Schools, Local Authorities, health professionals, commissioners and other support services should work together to ensure that children with medical conditions receive a full education. In some cases this will require flexibility and involve, for example, programmes of study that rely on part-time attendance at school in combination with alternative provision arranged by the Local Authority. Consideration may also be given to how children will be reintegrated back into school after periods of absence.

Communication with your school is key.

Consider the following steps:

- Speak to them as soon as possible
- Keep an open dialogue (e.g. emailing brief medical updates with appointment dates)
- Know your rights
- Request reasonable adjustments (and do this early)
- Get everyone involved to speak to each other
- Hold multidisciplinary and cross services meetings where possible
- Involve your child – find out what they want and need, what they are worried about and looking forward to.
- Keep being the best advocate you can be but find others that can fight your corner (it can be tiring doing it alone)
- Regular reviews
- Early and proportionate action
- Accept that mistakes will be made
- Learn from them
- Take one day at a time
- Remember that if they need to take time away from education this has happened in the past and children and young people can be supported to catch up in the future.

Support through the Graduated Response

The Graduated Response is a way of helping to identify the needs of children and young people with Special Educational Needs and Disabilities (SEND) and is described further in the **SEND code of practice** online.



www.gov.uk/government/publications/send-code-of-practice-0-to-25

Each Local Authority will also have their own Local Offer document on their website detailing how local services work together with parents/carers, schools and settings to improve the outcomes for children and young people with SEND.

The Graduated Response is a 'staged' approach and follows a four-stage process:

- Universal services (e.g. GPs, health visitors, early years settings, schools and colleges, etc.)
- School/setting SEND support
- Specialist SEND support (e.g. educational psychology, specialist teaching services, therapists, CAMHS, etc.)
- Statutory provision through an Education, Health and Care plan (EHCP).

Universal Support and Quality First Teaching

All pupils should be taught using 'Quality First Teaching' (QFT). This is an approach to teaching used in schools to ensure the effective inclusion of all pupils in high-quality personalised teaching.

QFT developed from a Department for Children, Schools and Families policy document called **DCSF-Personalised Learning (ioe.ac.uk), 2008**.



www.dera.ioe.ac.uk/8447/7/00844-2008DOM-EN_Redacted.pdf

It emphasised the importance of relationships between the classroom teacher and pupils and encouraged higher expectations through higher levels of support for all pupils to succeed in their education achievements.

As all children and young people make progress at different rates and learn in different ways, QFT means thinking about this and teaching appropriately using individualised strategies to meet the needs of most pupils.

The key features of QFT are:

- Clearly designed lesson plans with clear objectives
- Plenty of opportunities for pupil involvement and engagement with their learning
- Appropriate use of teacher modelling, explaining and questioning so that pupils can engage with higher level critical thinking skills
- Providing pupils with opportunities to interact both individually and in groups
- An expectation that pupils will take responsibility for their own learning and work independently
- Regular use of encouragement and (authentic) praise to engage and motivate pupils.

What do I do if my child needs more support?

If a parent thinks their child or young person needs more support in school the first people they should talk to are the class teacher/form tutor and SENCo. The SENCo is responsible for helping to make sure that the needs of the CYP with SEND are met. They will be able to say what support is already in place and talk through what should happen next.

Support is about making 'reasonable adjustments' and doing things a bit differently. It can include having a safe place or quiet room where the child can go to rest, thinking about where a child or young person sits in the classroom, providing extra help or specialist equipment and may also include making financial commitments.

All schools must publish a SEND Information Report on their website, and this will explain what they do to support children and young people with Special Educational Needs. If you still have concerns and would like to talk to someone who is independent you can contact your Local Authority's Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS) who are there to help and support families.

The majority of children with medical and physical needs will be able to have their needs met within the school's resources with reasonable short or long term adjustments.

[Also see pages 100 to 113 in the School Support section for more information on the Graduated Approach and reasonable adjustments.](#)

Travel to school support

Schemes vary and are provided by your Local Authority/Council. To find out which LA is responsible for provision for your child/young person use the following links:



England/Wales

www.gov.uk/apply-school-transport-for-child-with-special-educational-needs-sen

Scotland

www.mygov.scot/free-school-transport

Northern Ireland

www.eani.org.uk/help-available/home-to-school-transport

Ireland

www.gov.ie/en/service/school-transport/

Each LA will have their own policy, however the information below is about the responsibilities under the Education Act which should be the same across LAs although how they administer and deliver the support is likely to vary.

Responsibilities

It is the responsibility of parents and carers to ensure that their children attend school, and this includes the necessary travel arrangements to and from school.

The LA has a duty, and has powers, to make particular travel arrangements for children with special educational needs and disabilities, in order to facilitate their attendance at an appropriate education provision.

These responsibilities are set out in the Education Act 1996. It is important to note that the 2006 Act refers to travel rather than

transport. Therefore, travel assistance can consist of a range of options depending on the needs of the pupil. The key determining factor is whether the child:

Cannot be reasonably expected to walk to school because of their mobility problems or because of associated health and safety reasons related to their SEN.

Special travel arrangements will be considered in relation to the criteria and the individual needs whether or not the pupil has an Education, Health and Care Plan.

All LAs have a statutory duty to provide travel assistance for children aged between 5-16 years that have been assessed through an application process as eligible for the service. Similar services are run discretionarily for those in post-16 education.

Eligibility

Eligibility for home to school travel assistance is based upon the LA's published Home to School Travel Assistance Policy.

The LA will consider providing support for travel from home to school for pupils provided the following:

- The severity of the pupil's special educational needs prevents the parent carer from taking their child to school without assistance
- The pupil cannot travel independently to school due to physical needs
- It is expected that, where a child lives less than two/three miles from school (two for primary age, three for secondary age), the

parent/carer would be responsible for taking their child to school.

Parents of a child or young person that has been identified as eligible for home to school transport will be written to and asked to complete a Travel Care Plan.

Supporting evidence for eligibility

All cases will be considered on their individual merits in line with this policy and in accordance with statutory guidance. The following may be considered as part of the assessment when determining eligibility:

- The Education, Health and Care Plan and Annual Review reports
- Relevant professional reports
- Information about the nature and reasonableness of the route (e.g. journey times, changes, safety, nature of the pavements and roads, congestion, other passengers)
- Information submitted during the application
- Where travel training has taken place or is in progress, an existing Travel Training Plan (or assessment being undertaken)
- Evidence from a relevant Consultant if the parent/carer indicates that they are medically unfit to get their child to school
- Where evidence provided by the parent carer conflicts with the advice of other professionals, further clarification or evidence will be sought.

Personal Transport Budget

A personal transport budget is a sum of money that is paid to parents of a child that has been assessed as eligible for home to

school travel assistance. The personal transport budget scheme allows families the freedom to arrange their own travel arrangements with funds loaded onto a pre-paid card provided by the LA.

Personal transport budgets can be used to cover the cost of transport or travel services that are required to get the child or young person from their home address to their allocated school or college. Some examples of what a personal transport budget can be used for are below:

- Daily, weekly or monthly bus/train pass
- Fuel costs for parents who would prefer to drive their child or young person to school
- Taxi fares
- Arranging shared travel arrangements with other parents, such as shared driving responsibilities, buses or joint taxi bookings
- Overcoming barriers that may prevent you accompanying your child or young person to school, e.g. childcare
- Personal transport budgets cannot be used to purchase anything that is not related to the child or young person's home to school travel.

Long Covid Kids has developed a **template letter** in the resources section on **page 131** for you to use as evidence to support your application for school travel support. This letter outlines the reasons this reasonable adjustment is appropriate for some children living with Long Covid.

Additional specialist support at school

Additional specialist support that may be required to facilitate a safe return to school for some children:

- A support worker
- Medical support and emergency arrangements (e.g. in case of a fire alarm)
- Place of privacy for treatment (including to take medication)
- Immediate access to named pastoral support if there are any problems
- Specialist or individual tutoring
- Provision of materials in a different language (if English is not a first language, and cognitive difficulties make it harder to learn in English)
- Timetable and workload planning
- Mentoring and study support
- A plan to catch up on missed/key work
- The ability to drop subjects to enable a reduced timetable
- The ability to repeat a year
- Online/virtual school
- Individual home tuition
- Offering the ability to do the exam at home or virtually (where an invigilator may be sent to your home to support this)
- Rescheduling exams when two or more take place on the same day to allow rest and focused revision.

Based on the lived experience of members of our group there are some adjustments listed that although not commonplace, would be necessary for some children. Long Covid Kids will be campaigning for these changes. They may already be possible with appropriate healthcare assessment and advice if approved as part of a child's EHCP.

Contact Helpline

(For children & young people aged 0-25)

Contact run a helpline for parents and carers with a disabled child aged from birth to 25, living in any part of the UK. Your child does not need a diagnosis for you to call the FREE helpline: **Telephone 0808 808 3555.**

Disability Rights UK Student Helpline

(For children & young people aged 16 and over)

For further information on the support that is available for disabled students, please contact the FREE Disabled Students Helpline: **Telephone 0330 995 0414.**



Balance, hope & recovery

School/life balance or Occupational Balance

Who wants to use all of their available energy on school or work and have no energy left over for the fun things in life, or those things that are really important to keep us well and happy?

This can be a really common situation for people living with chronic illnesses such as Long Covid.

LCK starts from a principle that children and young people need to prioritise the things that are good for their health, e.g. taking time to convalesce, getting proper sleep and rest, eating and drinking well and attending healthcare appointments. And have a good balance between:

- The things they want to do, e.g. see friends, do fun activities, and
- The things they need to do, e.g. attend school.

This can be referred to as **Occupational Balance**. Occupations is a collective name for all the activities we do day-to-day. We want to support children to find this balance. Doing so provides the best chance to support their recovery. We can do this by:

- Listing everything that is happening in an individual child's life
- Supporting them to identify which are the most important
- Negotiation and compromise may be needed
- Listing what they find challenging
- Coming up with solutions to these challenges
- Implementing the solutions
- Reviewing whether they have worked.

Fostering hope

Living with a health condition often comes with a focus on what is 'wrong'. Sometimes doctors can't find anything 'wrong' on the tests that they are doing. This doesn't stop the child being or feeling unwell. Not finding a problem can make Long Covid more difficult to solve it. We can foster a sense of hope by shifting focus from symptoms and unknowns and challenges.

Let's enable children to recognise the positives in life by:

- Highlighting what they can do
- Naming what these things mean to them
- Showing them what they are good at
- Planning things to look forward to
- Planning time for laughter, silliness and fun
- Telling them and showing them how much they are loved and appreciated
- Letting them know about all the work that LCK and other advocates are doing to improve the situation of people living with Long Covid
- Encouraging them to use their experience to create change
- Spending time with friends or making new ones
- Concentrating on what they have control over
- Supporting them to see what they don't or can't have control over.

And try to:

- Be honest about what we do and don't know about Long Covid
- Be honest about what is or isn't likely to be beneficial
- Avoid false promises or assurances
- Avoid being too pessimistic or focussing only on the negatives.



After all, none of us know what breakthroughs and treatments are around the corner. This is not to say that we have to be positive all the time. Validating feelings of upset and frustration is important.

Remind children it is okay to not be okay.

What is recovery?

Recovery is a process that can look different for each child and can change over time.

Realistic expectations for recovery

Recovery is not static.
Recovery is not linear.
Recovery can not be accurately predicted with Long Covid (yet).

As more treatments are developed the expectations of what recovery is will also change. Healthcare professionals, school staff, parents and carers and children and young people can all have very different views on what recovery is.

With the above in mind, it is recognised as best practice:

- To invite everyone involved to meet to share and discuss views
- To identify the needs of each child
- To identify what is in the best interests of the child
- To agree to joint goals to make sure everyone is working toward the same outcomes
- To work out the steps that are needed to best meet the goals
- To work out who, or what service, will be responsible for each step.

Q&A

How long will Long Covid take to recover from?

We wish we had the answer. We just don't know. Recovery experiences vary and some people may not make a full recovery. Recovery can mean different things to different people at different points in time. It may depend on various factors such as age, where you live, available support and underlying conditions. Genetics may have a part to play.

We do know that most children seem to recover well after COVID-19 infection. Some will have a more typical Post Viral Infection/Fatigue that needs time and rest to resolve. Some will get better bit by bit as everyone works out what is wrong and treats each symptom. Some will find their symptoms are relapsing and remitting and may have to spend time learning how to manage symptoms.

Post Exertional Malaise/Symptom Exacerbation (PESE) has until now been considered to be one of the identifying features of ME/CFS and there is evidence about recovery (see [page 36](#)). But, it is

important to note that we don't yet know with a degree of certainty if people with Long Covid who experience PEM/PESE have ME/CFS or if the two conditions share some symptoms.

What we do know is that the sheer scale of the pandemic, and the vast amount of people with Long Covid means that science, research and best practice is moving at a rapid pace. See [page 74](#) for more support on working out how to use the information you hear.

The concept of Recovery is very individual too. See 'Balance, hope & recovery' on [page 86](#) and Goal Setting on [page 116](#) for more detail.

How can I move my child towards recovery?

There no quick fix.

Over the last two years LCK have observed the consequences of trying to 'push through'. This method is ill advised and may cause harm that may be permanent.

Our team have used their lived and professional experience

of supporting people with energy limitations to develop some resources to help. **Cautious Tortoise** and **Pacing Penguins** provide practical guidance to managing energy to support recovery.

How can I spot a relapse?

A relapse is when a health condition that had previously improved, worsens. For children and young people living with Long Covid this generally means their symptoms come back or affect them more than they usually do. It can be worth ruling out reinfection with COVID-19, especially if your CYP has been in contact with someone who has tested positive. PCR rather than Lateral Flow Tests (LFTs) should be used when someone is symptomatic – LFTs are used for asymptomatic monitoring.

It could also be a different infection such as another virus, a cold or the flu – many conditions have symptoms that overlap.

Should I seek private medical care?

It is widely recognised that

both the NHS and social services are stretched and this might mean a wait for treatment. In certain situations you may decide to seek help privately. Do make this decision cautiously. Talk to other parents of children with Long Covid to see who they recommend. Always make sure you know how much it is going to cost – ask about upfront and likely ongoing costs. Look at the website/literature provided by the service or practitioner.

Some professions have to register to be able to use their title. You can check that they are on the public register – and have met the criteria for practice.

Can charities help?

You may be able to seek support and funding from charities and voluntary services. Anyone working alone with your child must have Disclosure and Barring Service Clearance. Organisations have a responsibility to ensure that this is completed, monitored and kept up to date.

Should we get involved in research?

Taking part in quality research will improve our understanding of Long Covid and hopefully move us all towards treatment. Does the child want to be involved? Research is generally a positive thing, but not all research is equal. LCK is involved in a number of co-produced research projects and often shares opportunities with members. It is important that people living with Long Covid are involved from the start of research – to help design the research to make sure it is asking the right questions and looking to answer them in a way that will be helpful. For Health Research this is called Patient and Public Involvement (PPI). You can ask researchers what PPI they have had. We are unable to advise you which research to get involved with.

If you decide to take part in research you should:

- Have the opportunity to ask and get answered any questions you have
- Know exactly what you are signing up to and what is

- expected of you
- Know about the risks and benefits to taking part
- Consent to take part
- Accept that you may not know what group you or your child is placed in
- Not be discriminated against or treated unfairly if you decide not to take part (when invited)
- Know what will happen to your data if you decide to withdraw
- Be given the opportunity to see a copy of the results when the study is written up.



You can find out more on the National Institute of Health Research website. www.nihr.ac.uk

SUPPORT FOR SCHOOLS

Long Covid Kids

www.longcovidkids.org

Long Covid Kids have four main objectives: awareness, support, research and action.

We are pleased to be involved in co-producing international research in conjunction with international partners.

This is our first year as a charity due to the ongoing pandemic we have grown exponentially, in the near future we hope to secure funding that will enable us to invest in research and extend our services.

LCK currently offer online peer to peer support for families, children and young people via ChatBOX, LCK Connected and Facebook. Families report our Occupational Therapy zoom sessions have been invaluable. We plan to develop these to include play therapists, and youth workers.

Sign up to the blog or newsletter and follow us on social media to keep up to date with developments.

Remap

www.remap.org.uk

This is a brilliant charity that uses volunteers to custom make aids and adaptations to help disabled people live more independently. They usually do this where there is nothing available to purchase that will solve the particular challenge you are having.

Charity Commission

www.register-of-charities.charitycommission.gov.uk/charity-search

You can search the Charity Commission's register of charities too. Try putting in a diagnosis or your local area to see what is available. Your Local Authority/Council website might link to key ones in your area too.



Support for schools

Nelson Mandela is quoted as describing children as **"our greatest treasure and our future"** and describing that **"the true character of society is revealed in how it treats its children"**.

Similarly, teachers and schools are integral to so many aspects of children's growth, development and childhood experiences. They are in such a unique position because of the time children spend at school and this provides them with the opportunities to build relationships and offer support to both children and their families.

On top of the many challenges schools have faced during the pandemic, increasing numbers of children with Long Covid will mean significant new challenges for school staff. Children, young people and their families will look to schools for support to manage the devastating and wide-ranging impacts upon their lives and to help them access their education. They will need school staff to believe them, to understand and care and to support them with their learning and wellbeing.

"They may forget what you said but they will never forget how you made them feel." Carl W. Buehner

“

We launched our School Pack early 2021 following numerous enquiries from concerned school staff and parents. COVID-19 is airborne. With the aim of keeping schools safely open for all, Long Covid Kids began campaigning for improved indoor air quality for schools in the Autumn term of 2020. We continue to work collaboratively with all school communities through information sharing, support and signposting. We are pleased to support Co-Schools.

Long Covid Kids

Supporting pupils with medical conditions

Role and responsibilities of schools

From Supporting Pupils at School with Medical Conditions Statutory Guidance for Governing Bodies of Maintained Schools and Proprietors of Academies in England, December 2015 [Add shortened url here](#)

The governing body must **ensure that arrangements are in place to support pupils with medical conditions**. In doing so it should ensure that such children can access and enjoy the same opportunities at school as any other child.

Further advice: Schools, local authorities, health professionals, commissioners and other support services should **work together to ensure that children with medical conditions receive a full education**. In some cases this will require **flexibility** and involve, for example, programmes of study that rely on part-time attendance at school in combination with alternative provision arranged by the local authority. Consideration may also be given to how children will be reintegrated back into school after periods of absence.

In making their arrangements, governing bodies should take into account that many of the medical conditions that require support at school will affect quality of life and may be life-threatening. Some will be more obvious than others. Governing bodies should therefore ensure that **the focus is on the needs of each individual child and how their medical condition impacts on their school life**.

The governing body should **ensure that its arrangements give parents and pupils confidence in the school's ability to provide effective support for medical conditions in school**. The arrangements should **show an understanding of how medical conditions impact on a child's ability to learn, as well as increase confidence and promote self-care**. They should ensure that staff are properly trained to provide the support that pupils need.

Further advice: Children and young people with medical conditions **are entitled to a full education and have the same rights of admission to school as other children**. This means that no child with a medical condition can be denied admission or be prevented from taking up a place in school because arrangements for their medical condition have not been made. However, in line with their safeguarding duties, governing bodies should ensure that pupils' health is not put at unnecessary risk from, for example, infectious diseases. They therefore do not have to accept a child in school at times where it would be detrimental to the health of that child or others to do so.

Governing bodies must ensure that the arrangements they put in place are sufficient to meet their statutory responsibilities and should ensure that policies, plans, procedures and systems are properly and effectively implemented.

Roles within the school community

Headteachers

Headteachers should ensure that their school's policy is developed and effectively implemented with partners. This includes making sure that all staff are aware of the policy for supporting pupils with medical conditions and that they understand their role in its implementation. All necessary staff should be aware of the child's condition. Headteachers should also ensure that there are sufficiently trained numbers of staff available to implement the policy and deliver against all Individual Healthcare Plans (IHPs), including in contingency and emergency situations. This may involve recruiting a member of staff for this purpose. Headteachers have overall responsibility for the development of IHPs and need to make sure that school staff are appropriately insured and aware that they are insured to support pupils in this way. Contact with the school nursing service must be made in the case of any child who has a medical condition that may require support at school, but who has not yet been brought to the attention of the school nurse.

Parents

Parents should provide the school with sufficient and up-to-date information about their child's medical needs. They may in some cases be the first to notify the school that their child has a medical condition. Parents are key partners and should be involved in the development and review of their child's IHP, and may be involved in its drafting. They should carry out any action they have agreed to as part of its implementation, e.g. provide medicines and equipment and ensure they or another nominated adult are contactable at all times.

Pupils

Pupils with medical conditions will often be best placed to provide information about how their condition affects them. They should be fully involved in discussions about their medical support needs and contribute as much as possible to the development of, and comply with, their individual healthcare plan. Other pupils will often be sensitive to the needs of those with medical conditions.

School staff

Any member of school staff may be asked to provide support to pupils with medical conditions, including the administering of medicines, although they cannot be required to do so. Although administering medicines is not part of teachers' professional duties, they should take into account the needs of pupils with medical conditions that they teach. School staff should receive sufficient and suitable training and achieve the necessary level of competency before they take on responsibility to support children with medical conditions. Any member of school staff should know what to do and respond accordingly when they become aware that a pupil with a medical condition needs help.

School nurses

Every school has access to school nursing services. They are responsible for notifying the school when a child has been identified as having a medical condition which will require support in school. Wherever possible, they should do this before the child starts at the school. They would not usually have an extensive role in ensuring that schools are

Roles within the school community

taking appropriate steps to support children with medical conditions, but may support staff on implementing a child's IHP and provide advice and liaison, for example on training. School nurses can liaise with lead clinicians locally on appropriate support for the child and associated staff training needs; for example, there are good models of local specialist nursing teams offering training to local school staff, hosted by a local school. Community nursing teams will also be a valuable potential resource for a school seeking advice and support in relation to children with a medical condition.

Healthcare professionals

Other healthcare professionals, including GPs and Paediatricians, should notify the school nurse when a child has been identified as having a medical condition that will require support at school. They may provide advice on developing individual healthcare plans. Specialist local health teams may be able to provide support in schools for children with particular conditions (e.g. asthma, diabetes, epilepsy).

Clinical Commissioning Groups (CCGs)

CCGs commission other healthcare professionals such as specialist nurses. They should ensure that **commissioning is responsive to children's needs, and that health services are able to co-operate with schools supporting children with medical conditions**. They have a reciprocal duty to co-operate under Section 10 of the Children Act 2004 and must make **joint commissioning arrangements for education, health and care**

provision for children and young people with SEN or disabilities (as described above for Local Authorities). CCGs should be responsive to LAs and schools seeking to strengthen links between health services and schools, and consider how to encourage health services in providing support and advice (and they can also help with any potential issues or obstacles in relation to this). The local Health and Wellbeing Board will also provide a forum for LAs and CCGs to consider with other partners, including locally elected representatives, how to strengthen links between education, health and care settings. Since 2013 LAs have been responsible for commissioning public health services for school-aged children including school nursing. CCGs should be aware that this does not include clinical support for children in schools who have long-term conditions and disabilities, which remains a CCG commissioning responsibility. Children in special schools in particular may need care which falls outside the remit of LA commissioned school nurses, such as gastrostomy and tracheostomy care, or postural support. CCGs should ensure their commissioning arrangements are adequate to provide the ongoing support essential to the safety of these vulnerable children whilst in school.

Providers of health services

Providers of health services should **co-operate with schools that are supporting children with a medical condition, including appropriate communication, liaison with school nurses and other healthcare professionals such as specialist and children's community nurses,**

as well as participating in locally developed outreach and training. Health services can provide valuable support, information, advice and guidance to schools, and their staff, to support children with medical conditions at school.

Local Authorities (LAs)

LAs are commissioners of school nurses for maintained schools and academies. Under Section 10 of the Children Act 2004, they have a duty to promote co-operation between relevant partners – such as governing bodies of maintained schools, proprietors of academies, CCGs and NHS England – with a view to improving the wellbeing of children with regard to their physical and mental health, and their education, training and recreation. LAs and CCGs must make joint commissioning arrangements for education, health and care provision for children and young people with SEN or disabilities (Section 26 of the Children and Families Act 2014). LAs should provide **support, advice and guidance, including suitable training for school staff, to ensure that the support specified within IHPs can be delivered effectively. LAs should work with schools to support pupils with medical conditions to attend full-time. Where pupils would not receive a suitable education in a mainstream school because of their health needs, the LA has a duty to make other arrangements. Statutory guidance for LAs sets out that they should be ready to make arrangements under this duty when it is clear that a child will be away from school for 15 days or more because of health needs** (whether consecutive or cumulative across the school year).

Additional information on the role and responsibilities of the LA, From Ensuring a Good Education for Children who Cannot Attend School because of Health Needs: Statutory Guidance for Local Authorities, January 2013 Additional health needs guidance ([publishing.service.gov.uk](https://www.publishing.service.gov.uk))

LAs are responsible for arranging suitable full-time education for children of compulsory school age who, because of illness, would not receive suitable education without such provision. This applies whether or not the child is on the roll of a school and whatever the type of school they attend. It applies to children who are pupils in Academies, Free Schools, Special Schools and Independent Schools as well as those in maintained schools. The law does not define full-time education but children with health needs should have provision which is equivalent to the education they would receive in school. If they receive one-to-one tuition, for example, the hours of face-to-face provision could be fewer as the provision is more concentrated.

What children want their teacher to know

We asked children via their parents/caregivers on the Long Covid Kids Facebook Support Group if there was one thing that they wished their teacher(s) knew about their Long Covid. These were their responses:

EVERY MORNING I HAVE A HEADACHE, FEEL DIZZY AND SICK - EVERY DAY!

THERE CAN BE GOOD DAYS AND BAD DAYS. THINGS CAN BE GOING QUITE WELL UNTIL THEY'RE NOT AGAIN.

SOMETIMES I JUST CAN'T THINK STRAIGHT.

I AM TRYING TO PAY ATTENTION BUT MY BRAIN JUST WON'T WORK. IT'S TOO TIRED.

MY ACHES AND PAINS STOP ME FROM CONCENTRATING SOMETIMES SO I LOSE MY TRAIN OF THOUGHT.

PLEASE CHECK IF I AM OK INSTEAD OF ME HAVING TO APPROACH A TEACHER.

I WORRY ABOUT GETTING THERE ON TIME AND BEING EXHAUSTED WHEN I GET THERE.

JUST BECAUSE I AM AT SCHOOL DOES NOT MEAN I AM WELL.

I NEED YOU TO HAVE COMPASSION AND TO CARE, I AM NOT OK.

I AM WORRIED THAT YOU DON'T BELIEVE I AM SICK, I MAY SEEM OK, BUT THEN I AM NOT.

I MAY BE A BIT BETTER ONE DAY, OR WORSE ANOTHER, OR A WEEK LATER.

I MAY HAVE RESTED OVER CHRISTMAS BUT IT DOESN'T MEAN THAT I'LL BE BETTER WHEN I COME BACK TO SCHOOL.

I AM WORRIED THAT I MAY LOOK AND SEEM OK, BUT I AM NOT.

What parents want teachers to know

She may seem fine for the couple of lessons she's in for, but she gets home and sleeps the afternoon away.

Healing/recovery from Long Covid is not linear. There could be good days and bad days, so it's good to allow for some homework deadlines to be missed.

Just being at school takes all her energy. If she is at school, then that is all she can do that day. She is unable to do any activities out of school, socialise or do anything else.

Initially children may be too unwell to return to school. They will need gradual phasing back in. Rest and pacing will be key.

Doing too much one day can impact the next few days or weeks.

They are fighting a battle within their bodies every day to 'look normal'.

Just because they may be playing with their friends at breaktimes, doesn't mean they are not pushing themselves

She may look normal and healthy as she doesn't want to look weird, but that takes a lot of effort and she needs to rest from it at home after.

Trust them to manage their own symptoms, if they feel bad they will know that they need to rest that day. Don't cajole them into doing more than they feel able. Trust them, they aren't trying to get out of school, they would rather feel better.

This is an emotional rollercoaster for our children that they are not equipped to process. They are warriors.

They may be seen out at shops, restaurants, activities. This doesn't mean that they are ok for fulltime school, they might have had a sleep beforehand or a planned rest afterwards. Just because they are not in full-time school doesn't mean that they need to live an isolated life with no fun.

If they say that they have reached their limit for that day/lesson and need to go home, let them.

Believe them when they say that their brain fog is bad and they don't understand despite it being explained over and over.

Brain fog is real. Something as simple as reading out loud can be hard and frustrating because sometimes their brain just gives up on them.

It's different from just being tired, it's debilitating.

Above all else, please work with parents and show empathy and compassion.

Know that it is a big achievement for children living with Long Covid to even make it into school. Know that the medics simply don't have answers and we don't know how long our children will suffer long covid or if they will ever recover.

What do staff need to know?

Spotting Long Covid

It is highly likely that you will have encountered a child who is living with Long Covid due to the high numbers of children infected with COVID. Unfortunately, they might not know that this is what is happening to them.

We have outlined the signs and symptoms of Long Covid and the conditions that might come along with it in Section Two of this guide, page 19. To improve case findings in the community we are asking schools to '**Spot Long Covid**'. Please keep this in mind for any children who:

- Might be struggling with their health
- Have a change in health
- Frequently complain of a mixture of symptoms
- Seem particularly exhausted or distracted after a COVID-19 infection
- Return to school after infection and seem fine, and then develop new health issues weeks or months later

As discussed in the section on PANS (see **page 32**) some children can display developmental regression and sudden difficulties with writing and maths skills. Look out for children who show signs of:

- Cognitive fatigue as well as physical exhaustion
- Struggling to follow a lesson
- An increase in forgetfulness or who ask frequent questions or for more support.
- Daydreaming
- May have brain fog or be in pain.

Be inquisitive of behavioural changes and speak to the child outside of the classroom

environment to see if they can explain what is happening for them. Some children living with Long Covid will complain of vague symptoms such as:

- Stomach complaints
- Pains in their limbs or tiredness
- Headaches
- Sore feet
- Metallic taste
- Odd smells
- Nausea
- Visual disturbances,
- Temperature dysregulation

The symptoms of Long Covid are such that children, especially younger children, may have difficulty articulating them. Look out for clusters or patterns of symptoms. Please try to listen.

LongCovid can cause sudden long-term debilitating health challenges. There is no treatment and no cure for Long Covid yet. Alongside the physical challenges, infection can cause anxiety and depression which can be exacerbated by the uncertainty of the child's future recovery.

While many children do recover well, some children have been reporting significant symptoms that impact daily life for two years. As with any new or worsening symptom, ongoing symptoms should be seen by doctor.

The graduated approach & reasonable adjustments

The graduated approach

The graduated approach, also known as SEND Support, is a way of helping to identify the needs of children and young people with Special Educational Needs and Disabilities (SEND).

This is a 'staged' approach to help children and young people learn and make progress and follows a four-part cycle (assess, plan, do and review).

The SEN Support for each child will be different because it is designed to meet the needs of an individual child or young person. It should be set out in a plan and include the actions and approaches needed to help the child make expected progress.

SEN support could include, for example:

- Additional materials and/or equipment
- Interventions or programmes for the individual child
- Interventions in small groups
- Focused work with the class teacher, SENCo or other school staff
- Support for a child to join in class activities or interact with other pupils
- Advice and support from other professionals for the school staff, e.g. specialist teacher, an educational psychologist, occupational therapist, physiotherapist or a speech and language therapist.

For a child or young person living with Long Covid, this might also mean:

- Modifications to physical access and the physical environment

- Modifications to curriculum access and curriculum content
- Liaison with appropriately trained staff who can focus on health care needs
- Support with social and emotional needs

Statutory guidance in this area is outlined in the DfE document **Supporting pupils at school with medical conditions**.



www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

The main points from it are:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education.
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions.
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported.

The school, setting, or parents can consider requesting an **Education, Health and Care Needs assessment** if a child or young person has not made expected progress following the assess – plan – do – review cycle. Details of how to do this will be on each LA's Local Offer page.

If you would like more information or help completing the forms, you can contact your LA's Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS) who are there to help and support families.

Links needed to reference other countries:
[Wales placeholder, what is the process](#)
[Scotland placeholder what is the process](#)
[Northern Ireland placeholder what is the process](#)

Reasonable adjustments

'Reasonable adjustments' are changes that must be made in order to remove or reduce a disadvantage that someone experiences due to their disability.

They could involve making changes to:

- The environment or facilities (adding or removing things from them)
- Equipment provided
- Services provided
- The way things are done
- Policies and procedures that disadvantage people with disabilities
- Providing information in an accessible way

Or:

- Providing specialised equipment
- Getting someone in to support them

What is considered a 'reasonable adjustment' depends on individual circumstances.

The school needs to consider carefully if the adjustment:

- Will remove or reduce the disadvantage for the person with the disability

- Is practical to make
- Is affordable by the school
- Could harm the health and safety of others

Long Covid Kids are unable to give a legal opinion on what is and is not a reasonable adjustment.

How does the Equality Act 2010 and provision of reasonable adjustments apply to schools?



The duties for schools in the Act, including the duty for schools to make reasonable adjustments for disabled children, are designed to dovetail with duties under the Special Educational Needs (SEN) framework which are based on a separate definition of special educational needs. Further information on these duties can be found in the SEND Code of Practice and the Equality and Human Rights Commission's Codes of Practice for Education. **From Gov.uk.**

It is not necessary to wait to determine if a child living with Long Covid will fall under the definition of disabled according to the Act.

Initiating reasonable adjustments will improve the opportunities for children to access education, maintain friendships and support long-term emotional wellbeing.

Adjustments can be put in place informally where they are general or readily available. They can be formalised through an Individual Health Plan (IHP) or Education Health and Care Plan (EHCP) when more individualised

The graduated approach & reasonable adjustments

support or additional funding is required. Charitable funding is another avenue that can be explored locally.

Who is responsible for making these arrangements?

- The Local Authority. This applies even if you are elective home schooling (each council local authority will provide different things) - in this case **caregivers have certain duties** too).
- The education provider. Including schools, colleges or apprenticeships.
- Special Educational Needs and Disabilities Coordinator (SENDco/SENCo) or similar
- Each teacher or teaching assistant who supports the child.
- External examining boards or providers.



www.gov.uk/government/publications/elective-home-education

Adjustments can be complex and will take time to arrange. Additional assessments may be required. Starting discussions with the school early is advised.

Children and young people with Long Covid are likely to need a period of time where they can focus solely on their health, rest and recover energy. They might also need to access healthcare and rehabilitation during this time. They may not be well enough to attend school or participate in education during this period.

This time can be used to initiate early discussions with the school, and to support

children to feel more connected to school life. This will make the return to school quicker and more sustainable as well as supporting recovery.

Examples of reasonable adjustments

Disability Rights UK has a comprehensive **list of potential adjustments** that could be made by schools/colleges.



Disability Rights UK
bit.ly/3wv1Lxp

Some of these will also be relevant to children learning at home. Long Covid Kids have identified some adjustments that are likely to be particularly relevant for children living with Long Covid.

Consider universal changes in the classroom that could help

Some children and young people, or their caregivers, may be reluctant to adopt some of the strategies we suggest due to stigma. Where possible consider universal changes to improve inclusion. See also the graduated response document in this pack for further support that can be provided at a universal or whole class level.

Examples include:

- Implementing regular short breaks in learning
- Finishing lessons a few minutes early so they don't have to rush to get to their next lesson or switch their learning so quickly
- Building in extra time at the end of lessons to check their understanding of what they have just learnt

- Reminding children to change their posture or stretch
- Offering a hard copy of materials usually presented virtually
- Supplying accessible and timely notes or catch up material for anyone who has to miss a lesson
- Reading out what is written on a whiteboard
- Staff role modelling treating children/young people with Long Covid with confidentiality, respect, understanding of their needs and putting adjustment in place without drawing attention to them
- Awareness training for school staff
- Using peer and buddy support for all students
- Having regular supportive check-ins or contact with staff if they have to be away from school for any length of time.

Phased, extended and hybrid return to/remain at school options

Many children living with Long Covid are likely to have had considerable time away from education. Some children may be attending school and struggling.

- Children who are struggling should be identified for support.
- They are likely to need to attend school very part time to rebuild their tolerance to activity.
- Attending school should be increased slowly and sustainably.
- Children may need to start off with as little as an hour once a week.

For more specific guidance on what phased, extended and hybrid returns to school might look like elsewhere in the pack, visit [url here](#).

Attending in-person learning involves getting up and ready for school and getting to school which uses more energy. Hybrid options, which involve online and home learning, could be considered and may be more sustainable.

When considering attendance, include classes that CYP enjoy alongside core subjects. Where possible try to include social time with friends. This may need to be prearranged in a quiet room rather than on the playground at first.

Supporting a phased, extended or hybrid return may also require provision of support with transport. Additional information about this is provided on **page 82** and a template support letter is in the resources section on **page 131**.

Flexibility in attendance

Avoid focusing on attendance. Attendance awards can be detrimental to the mental wellbeing of children and young people with chronic ill health or disabilities. Children living with Long Covid need 'permission' to prioritise rest and recovery.

Long Covid is a relapsing and remitting episodic health condition. Children living with Long Covid can have better days where attending school is possible, and they can have days where attending school is not achievable. They will also need time to attend medical investigations and treatments.

Provision for short, frequent rest breaks

Having short, frequent rests is a well recognised pacing method (see our **Pacing Penguins**

The graduated approach & reasonable adjustments

poster in the resources section). Some children are able to regulate this themselves as long as they know they have 'permission', e.g. to close their eyes or put their head down on the desk for a few minutes.

Many children will need access to a quiet environment to manage their symptoms. Enabling children to leave the classroom as required is reassuring and may improve attendance. An 'exit card' can be supportive, and less disruptive for the class, e.g. this could be used if they need the toilet urgently, or five minutes before the end of class to give them extra time to move between rooms when the corridors are quiet.

If there is no rest room available, making a chair available outside the class along with the exit card may provide enough of a break for some children, and provide an opportunity to rejoin the class again in a timely manner. Like all strategies this would be symptom dependent and success could vary from day to day.

Specialist equipment in the classroom

Examples include:

- Wearing sunglasses or tinted glasses to reduce the impact of lighting
- Wearing in-ear devices or headphones to reduce the impact of noise
- Use a laptop or tablet instead of having to handwrite
- Use a dictaphone to record lessons if they have to step out or because of difficulties with concentration
- Using fidgets for concentration

- Using a wheelchair to mobilise around the school
- Using a hat, coat or blanket to maintain temperature

Consideration for adjustments to physical education

Children and young people who experience Post Exertional Symptom Exacerbation (PESE) may need to avoid Physical Education lessons. In the US the **American Academy of Paediatrics** suggests that all children and young people who have had COVID-19 should have cardiac screening before returning to physical activity. Please make sure they have been reviewed by their GP at a minimum, and a Cardiologist if they have cardiac symptoms such as palpitations or tachycardia (fast heart rate).



www.world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf

Children who are unable to participate in PE require alternative provision and should not be asked to sit and watch their peers unless they elect to. PE sessions can be used as additional rest breaks, or time to catch up on learning when appropriate.

In the longer term, alternative gentle physical activities may be considered with appropriate professional guidance.

NICE cautions against the use of **Graded Exercise Therapy** in children living with Long Covid who have PESE or a diagnosis of ME/CFS. Please see the Long COVID Physio

resources on **physical activity, exercise and safe rehabilitation**.



www.bmj.com/content/370/bmj.m2912
www.bjsm.bmj.com/content/early/2021/12/01/bjsports-2021-104281

Adjustments to exams and assessments

Access arrangements allow those with special education needs, disabilities or temporary injuries to access an assessment without changing the integrity or demands of the assessment. These adjustments can be made based on evidence of need and normal ways of working. They need to be applied for in advance of the exams.

Reasonable adjustments are required when 'a disabled person would be at a substantial disadvantage' in doing the assessment otherwise (The Equality Act, 2010). Reasonable adjustments can be unique to each child according to their individual needs.

Special Considerations are an adjustment to a child's mark or grade after the exam due to temporary illness, injury or other factor at the time of the exam.

Find out who within your school is responsible for deciding on and applying for access arrangements and speak to them about the arrangements your child will need. Some schools have a dedicated exams officer, or you could talk to your child's head of year or SENDCo. You can also find further information at the

Joint Council for Qualifications website as well as on each exam board's own website.



www.jcq.org.uk

Access arrangements and adjustments include:

- Additional time in the exam
- Extensions to submission dates for coursework
- The option for oral presentations alongside or in place of written work
- Provision to take supervised rest breaks
- The opportunity for snacks and drinks
- The options to use memory aids for formulas (maths, science) or texts (English)
- Providing exam papers in a preferred format e.g. digitally, on coloured paper, with larger font
- The option to type rather than handwrite
- A reader, scribe or prompter (who is given time to prepare for their role)
- A separate room

Travel to school support and additional specialist support

For information on travel to school support, refer to the Support for Parents and Caregivers section – Travel to school support, **page 82**; Additional specialist support and helplines, **page 84**.

Areas of need & things to consider

Although Long Covid may not immediately be considered a disability, Long Covid Kids would urge schools to take note of the reasonable adjustments outlined from **page 102** and implement them as soon as possible. By reducing pressure and increasing support our aim is to reduce the negative impact that pushing through when children and young people should be focusing on rest and recovery.

One of the biggest adjustments that students with Long Covid will need is support to rest and pace throughout the school day (and at home).

We have produced a guide on what phased, extended and hybrid return to/remains in school might look like. Again this will be specific to the individual and based on the severity of their symptoms. [See url here](#)

Children's families also have widely different experiences. Unfortunately we know of many families where a parent may also have Long Covid or where there are a number of siblings with Long Covid, or sadly where families have lost a member due to acute COVID-19 infection. Some families will be able to afford to take time off work to care for their child, and others may have little choice but to send them into school. Speak to the families openly to learn about their experience and family situation and signpost them to support services such as social workers as needed.

Do make sure to get your school's SENDco (or similar involved). They can help with planning to help a student return to or remain in school

What will help children and young people with Long Covid in School?

Long Covid is a physical condition which can affect any part of the body and can cause different symptoms at different times for different children and young people. There is not a one size fits all approach and not every CYP will have all the difficulties outlined in the following table. Initially after a SARS-CoV-2 infection, some children may be too unwell to attend school. As they return, please also refer to **Cautious Tortoise** and the **Pacing Penguins** guidelines.

Areas of need	Difficulties you might see in school	Things to consider
Communication and interaction	<p>Reduced ability to find words or express themselves when feeling fatigued, anxious or when they do not understand a task.</p> <p>Reduced ability to understand and remember verbal information or instructions.</p>	<ul style="list-style-type: none"> • Use of a 'secret signal' which only the child and their teacher(s) are aware of, that can be used to communicate when they feel anxious, fatigued or need help or a break. • Break instructions down into smaller chunks, repeat instructions, check out with the child that they have understood, ask them to repeat or run through what they have to do and provide a visual break down/reminder of steps to complete. • Use simplified language, shorter sentences and visual supports and prompts to reinforce verbally presented information.
Cognition and learning	Fatigue and tiredness.	<ul style="list-style-type: none"> • Rest breaks during tasks, lessons or exams. • Provide a quiet place to rest during breaks or lunchtimes. • Use of an exit card to leave the classroom without question when needed. • A card or signal that they can use to ask for help or to show that they do not understand or need a break. • Extra time for tasks or exams. • Flexibility regarding homework or exams. • Reduced attendance or reduced timetables. • Opportunities to learn from home or online when physically being 'in school' is too difficult. • Increased differentiation or non-attendance during PE lessons. Liaise with health professionals as needed.

Areas of need & things to consider

Areas of need	Difficulties you might see in school	Things to consider
Cognition & learning	Difficulties with concentration, memory, brain fog and headaches.	<ul style="list-style-type: none"> • Short tasks broken down into small steps and chunked up into sections that can be worked through in a logical order and can be ticked-off . • Simplified task prompt sheets that are reinforced with visual prompts. • Recording part of a lesson, so that it can be referred back to. • Clear instructions and support to start a task. • Clear task expectations. • Clear end point for each task (with clarity on what the finished task will look like or a specified end time). • Visual prompts, structures, checklists, timetables or reminders. • Practical activities, physical objects and opportunities for experiential learning to make tasks as concrete as possible. • Mind maps/flow diagrams to record ideas visually. • Increased differentiation of tasks. • Rest or brain breaks. • Reduce distractions in the environment to facilitate concentration, e.g. sit nearer to the teacher or away from windows or doors. • Opportunities for pre-teaching, repetition, reinforcement and overlearning to support retention of knowledge and generalisation of skills. • Banks of key words, especially for topic work or specific subject vocabulary.

Areas of need	Difficulties you might see in school	Things to consider
Cognition & learning	Difficulties with concentration, memory, brain fog and headaches.	<ul style="list-style-type: none"> • Reduce the amount of reading required to obtain information. Use alternatives such as pictures, cartoons and video, paired reading with a work 'buddy', tape recordings of source material, simplified texts, diagrams, flow charts, etc. • Reduce the amount of writing or copying from the white board required. Use alternative equipment such as a laptop or a mini whiteboard and techniques such as note taking, mind mapping, etc.
	Gaps in learning (due to missed school/ reduced attendance) or due to a regression of skills.	<ul style="list-style-type: none"> • Monitor progress carefully, highlighting gaps in learning and planning individualised support to fill these. • Continued contact with parents/carers to keep them up to date with progress.
Social, emotional and mental health difficulties	Anxiety caused by the duration and severity of difficulties, a lack of understanding, unknown timescales for recovery, missed school or missed opportunities to socialise (see below). A covid infection can also cause anxiety.	<ul style="list-style-type: none"> • A keyworker to build a relationship with, to talk to and who will listen, such as an Emotional Literacy Support Assistant (ELSA), learning mentor, Thrive practitioner, Education Mental Health Practitioner (EMHP) or equivalent. • Support to work on recognising, naming and expressing feelings and support to cope with strong feelings and to communicate how they are feeling about their situation. • Emotional Literacy resources such as use of role play/ mirror games, videos, songs, emotion cards, games, stories and puppets. • Wellbeing check-ins. • Social Stories or Therapeutic Stories.

Areas of need & things to consider

Areas of need	Difficulties you might see in school	Things to consider
Social, emotional and mental health difficulties	Anxiety caused by the duration and severity of difficulties, a lack of understanding, unknown timescales for recovery, missed school or missed opportunities to socialise (see below). A COVID-19 infection can also cause anxiety.	<ul style="list-style-type: none"> • Evidence-based anxiety intervention.s • Use of Cognitive Behaviour Therapy (CBT) informed approaches to understand the link between thoughts, feelings and actions. Diaries, feelings diaries or rating scales, etc. • Opportunities to express themselves and their feelings through art, drama, dance, sport, etc. • Relaxation, mindfulness, calming activities and breathing exercises. Please see the LCK Padlets on page X and Wellbeing for Children on page 28 for further examples. • A nurturing learning environment with staff that understand the child's needs will enable them to feel safe and secure and well cared for so that they can focus on getting better (and later to access their learning). • Understanding that non-attendance due to Long Covid is likely to have different underlying causes to emotionally based school non-attendance.

Areas of need	Difficulties you might see in school	Things to consider
Social, emotional and mental health difficulties	<p>Social isolation (due to not being able to attend school fulltime, not being well enough to socialise with peers out of school, attending more medical appointments or taking part in less out of school activities or sports clubs).</p> <p>A lack of school 'belonging' (due to being absent from school for a period of time or not being able to attend fulltime).</p>	<ul style="list-style-type: none"> • Check-ins from key member of school staff such as class teacher, form tutor or key adult with whom the child can establish/maintain supportive trusting relationships. • Keeping the child in mind and including them in all school activities to ensure a sense of school belonging (include the child and their parents in planning if needed). This will also ensure that the child has equal opportunities and an equality of access to their education. • Additional opportunities for making connections, social interaction and developing or maintaining relationships, e.g. social skills groups, friendship groups, circle of friends approaches or peer mentoring/buddy systems. • Use of online platforms to keep in touch with friends and classmates when physically unable to attend school. • Be alert to the possibility of stigma and a lack of understanding in other children and young people leading to unkind words, e.g. that the child with Long Covid is 'faking it' or doesn't look ill. Work with classmates and peers to understand differences in others and to promote understanding, acceptance and kindness. • Close and supportive home/school liaison to enable the child to see that both home and school are working closely together to support them.

Areas of need & things to consider

Areas of need	Difficulties you might see in school	Things to consider
Social, emotional and mental health difficulties	<p>Loss of identity and changes to sense of self (due to reduced school attendance and not being able to take part in social activities, hobbies and sports which they previously defined themselves by) and resultant impact on self-esteem.</p> <p>Reduced self-esteem due to changes in sense of self or awareness of increased difficulties with learning.</p>	<ul style="list-style-type: none"> • Use principles from Acceptance and Commitment Therapy (ACT) to work on acceptance (accepting a change in self/identity and accepting what is outside of the child's control), being present, recognising strengths and values and setting goals. • Opportunities to develop and share strengths and achievements with others. Use of diaries, records of achievements, etc. • Resilience building activities. Explicitly teach problem-solving skills and self-regulation strategies in response to adversity, e.g. ask questions such as "what would x do?", "what has worked before?", "how can we break this big problem into little pieces?" • Self-esteem building activities so that the child experiences success and feels a sense of pride in their achievements. • Use specific praise which emphasises the effort and the approaches the child used as well as the end result. • Use pre-teaching to increase confidence with learning. • Design errorless learning tasks or tasks with a reduced level of challenge that the child can attempt independently and experience success with. Challenge can then be gradually increased with success. • Use self-monitoring charts, record progress visually or keep a diary of achievements which the child can look back at or share with key adults and parents/carers.

Areas of need	Difficulties you might see in school	Things to consider
Sensory and/or physical needs	Sensory sensitivities to noise and light. Vision difficulties and sensitivities to smell and taste	<ul style="list-style-type: none"> • Be aware that busy, noisy spaces such as the lunch hall may feel overwhelming and provide alternatives. • Access to quiet spaces.
	Physical symptoms, such as gastrointestinal issues, chest pain, heart palpitations, joint or muscle pain, dizziness, nausea, headaches, fevers, nerve pain, etc.	<ul style="list-style-type: none"> • Exit card so that the child can leave the classroom if needed. • Have an individual healthcare plan in place in liaison with the school nurse and other professionals such as paediatrician, OT and PT (as appropriate).
	And...	<ul style="list-style-type: none"> • Listen and support children, young people and their families. • Consider the impact upon families including siblings. • Seek the views of children and young people; ask them what would help them and how they would like to be supported. • Be flexible and consider the individual child's individual needs; that these may fluctuate over time and adapt the child's support plan as and when needed. • Consider that the child's focus may need to be on getting better and wellbeing and that this may need to take priority over attendance and learning for a while. • Liaise with any involved health professionals and discuss the impact on learning with your school Educational Psychologist (as appropriate and negotiated).

Goal setting

Goal Setting

Another recognised way to foster hope is by setting joint goals in collaboration with everyone involved in the child's care in order to balance and negotiate priorities.

Goal setting process

- Include the child in the discussion wherever possible (or via an advocate)
- Identify and prioritise alongside parents carers goals
- Agree and record goals with the child, parent and team
- Describe the current level of performance
- Describe expected level of achievement performance by intended date
- List goal related parameters (limits/boundaries)
- List plans of action
- Allocate actions
- Plan intervention/treatments
- Review goal as part of evaluation.

There are lots of different ways to set out goals. We will share a few of them here that may be the most useful for children with Long Covid.

SMART Goals

In a twist on the well known concept of SMART Goals try setting SMORT Goals instead:

- Specific**
- Measurable**
- Occupation-centred** (i.e. focused on activity/occupation/task)
- Relevant** (alternatively realistic, reasonable or rewarding; meaningful and motivational)
- Time-orientated** (alternatively time based or timed)

Making goal setting easy by using a formula

In/By
(When? Number of days/weeks/months)

Name
(Who? Name of the child)

Will
(Do what? Which occupation, activity, task?)

By
.....
(How? Level and/or type of support, accuracy/quality of performance, frequency or duration)

Where
.....
(What will the environment(s) be like).

Long term and short term goals

We break goals down into both long term 'end goals' and short term, more achievable goals or 'milestones'. Goals need to be realistic, measurable and set within a

timeframe to support hope. Sometimes we don't know what is causing the difficulties when we set the goals and need to do extra work to find out what is happening.

Goals are based on activities rather than symptoms to make them meaningful to children.	Baseline Occupational Performance (OP) Issue	Long-term goal	Short-term goals
Sarah's goal is about difficulty dressing. This could be due to limb weakness or ability to sit up but we don't just focus on limb movement or sitting.	Self-care: Sarah requires considerable assistance from her parents when getting dressed, in particular when putting on a jumper or T-Shirt (short and long sleeved).	In 3 months Sarah will be able to independently put on diverse jumpers and T-shirts (varied styles) in a calm environment without time pressure.	In 4 weeks Sarah will put on a short sleeved T-shirt with assistance. In 8 weeks , Sarah will put on a widely cut, long-sleeved top with verbal prompting and pointing only.
Sanjay's goal is about setting up and tidying his workspace. This could be due to cognitive difficulties with attention, memory or planning but we don't just say he should improve these.	School work: The teacher identified Sanjay has difficulties organising his work space and work materials to get ready for school work.	By the end of the term Sanjay will independently set up and tidy up his work space (incl. materials and tools required), 3 out of 5 times.	By term week 4 Sanjay will set up his workspace with prompts from the teaching assistant. By term week 8 Sanjay will tidy up his work space after finishing school work using clues from peers.
Tom's goal is about attending Scouts. This could be because he is experiencing fatigue OR anxiety but we don't focus on removing these (that might not even be possible)	Leisure/recreation: Tom would like to be able to go back to Scouts. Currently he is managing to sit and concentrate on a video call with friends for around 20 minutes with no worsening of symptoms.	By the end of June Tom will be able to attend a full session of Scouts at least once a fortnight, and whilst there independently make use of appropriate rest breaks to manage symptoms.	By the end of April Tom will attend half an hour of his Scouts session with support from his parents. By the end of May Tom will attend one hour of his Scouts session with help from Scout leaders and rest breaks.

Goal setting

continued

Goal outcomes

Goals might not always lead to complete independence in an activity.

Adaptations may need to be made to the activity or environment to ensure success. For example:

- Sarah needs a calm environment with no time pressure.

Some goal parameters even allow for inconsistent achievement of tasks. For example:

- Sanjay might still need support 2 out of 5 times (through prompting or physical support)
- Tom might not manage to attend a full session of Scouts every week.

This demonstrates how no one is 100% perfect. Building this into goal setting allows for fluctuations in the Long Covid condition.

Reviewing goals

Review date: To be agreed when setting goals (can be changed if required and agreed)

Review meeting: Could be done in person/ by phone/videocall/e-mail/post

Collaborative decision making: Deciding if the goal was achieved?

Abbreviations Key:

Achieved **(A)**

Partially Achieved **(PA)**

Not Achieved **(NA)**

If a goal was not achieved, identify why you think that was. Was it because, potentially:

- The goal was set too high
- Not enough time was given to achieve the goal
- Something unexpected arose, e.g. a relapse of symptoms, therapy staff sickness
- The goal was no longer relevant
- Priorities changed.

Knowing why a goal wasn't achieved supports future goal setting. It can also identify when achieving a goal was out of an individual's control.

From goal to action plan

Adapting the activity, or the environment can support goal attainment. Goal achievement is not always reliant on improvement in individual ability.

We can also add in physical support, or verbal or physical prompting to achieve a goal and support a child to take part in a balance of activities.

Goals

- Focus on changes in occupational performance and the ability to engage in or perform a specific activity or task
- Focus on changes in the ability to play, complete school work/homework, perform self-care activities or engage in leisure activities
- Seek improvements in common childhood and family occupations.



An action plan

Looks at the methods we use to achieve goals and can include:

- Coaching parents/carers/school staff/child
- Strategies provided to parents/carers school staff/child
- Equipment provided (e.g. seating, adapted eating utensils)
- Environmental modifications
- Activity/task adaptations
- Direct intervention
- Level of physical/verbal prompting needed
- Practice (remember practice makes progress not perfection)
- Medical treatment/medication.

In Long Covid, making practice part of everyday activities will support children to keep within their energy limits. This is particularly important if they experience Post Exertional Symptom Exacerbation (PESE).

Goal Setting section based on an unpublished conference presentation that the LCK Occupational Therapist Kirsty Stanley completed with colleagues Andrea Hasselbusch and Dr Carolyn Dunford in 2013, called: **Collaborative Goal Setting with Children, Young People and Families.**

For more information see [URL link here?](#)



Mitigating risk

Copy needed

Q&A

How do I spot the signs of cognitive/physical/psychological/social or sensory deterioration so I know when to suggest they take a break?

All activities require energy and the types of activities a child with Long Covid finds the most draining will vary from child to child. They might only learn what they find difficult as they start to do more.

Some will find physical activity fatiguing, such as walking, carrying, stretching, handwriting (or even sitting).

Signs of physical deterioration:

Pain, visible exhaustion, headaches, complaints of sore or heavy limbs, stretching, rubbing or shaking limbs/muscles/joints. In severe cases weakness, inability to move or episodes of collapse, complaints of dizziness or palpitations.

Some will find cognitive activity fatiguing such as concentrating, thinking, remembering, problem solving, writing, answering questions.

Signs of cognitive deterioration:

Delayed or slow responses, always saying they don't know, making mistakes with simple tasks, not completing work, poor recall, difficulty making decisions and taking much longer with a task that it should take (e.g. doing 2 maths questions in the same time that others complete 12).

Some will find psychological things fatiguing – activities where there are high levels of emotion involved such as laughing with friends, falling out with friends, being bullied, sad or anxious, or feeling like they don't know something or find things more difficult than expected.

Signs of psychological deterioration:

Emotional lability; crying, anger, frustration, withdrawal, irritability, self-criticism, hyper awareness of criticism.

Some will find social activities difficult such as taking part in conversations. Some children with Long Covid might have also developed stutters or tics.

Signs of social deterioration: withdrawal:

Not participating, not answering a question appropriately or quickly enough, an increase in a stutter or tics.

Some children develop sensory processing difficulties which can make bright lighting, flickering lights, noise (pitch, volume or multiple noises) and extremes of temperature overwhelming and intolerable. Some will have changes to their sense of smell or taste which might impact them at lunchtimes. Some might have difficulties with touch. Having a quieter room where they can take time out from sensory overload will be important for these children.

Signs of sensory deterioration:

Complaining of headaches, sore eyes, that things are too loud or bright. Increased sensitivity to smells, coughing. Calling out in pain if knocked or touched.

One of the things that is most difficult with pacing is that children feel fine whilst doing an activity, it's later when the impact of that exertion becomes known.

Often children worry about missing out or having to catch up. Thinking about how you structure lessons generally may be worth doing as a teaching group – can you switch tasks, make clear indications of switches, take mini movement or mindful breaks, etc. The reasonable adjustment guide contains more ideas for generalised adjustments.

Should I push children to try and finish a piece of work or just let it go?

This entirely depends on how important the piece of work is and how much the child is struggling with symptoms. If they are regularly finding it difficult to complete work then this may be a sign that they need more support, or may need to pull back attendance.

If you can ascertain their understanding of a topic in another way then try to do this instead.

You could also consider giving them extra time to complete the task but do not keep them back during rest breaks to do so. They will

need these breaks for their health.

How do I know when it's time to send them home to rest and not keep them in school?

As discussed above children do not live in isolation and each family will have its own unique set of circumstances. If reasonable adjustments are put in place (ideally with support of healthcare professionals/SENDco), followed and regularly reviewed it is our hope that children will not experience a relapse. However, Long Covid is a new and unpredictable condition.

A simple rule of thumb might have been – if you would have sent a child without Long Covid with those symptoms home then send them home. However, children with Long Covid will still experience symptoms. Attending school whilst unwell should be done with negotiation and an agreed plan of action for times when symptoms become too much.

Symptoms could be successfully managed by

following the child's support plan or by taking an additional rest break. If the child is no better after a half an hour rest break consider sending home.

Similarly is the child is distressed (cannot be soothed) or appears to be in pain, contact their parents.

Do seek medical support if needed too.

How much PE can children living with Long Covid do?

Please see the guidance on this in the **Cautious Tortoise** and **Pacing Penguins** resources and **Reasonable Adjustments** on **page 102**.

This will depend on a number of factors such as symptoms and experience of Post Exertional Symptom Exacerbation. Long Covid Kids advises caution and we recommend asking your child's GP to agree their participation in physical exercise before engaging in it.

In Section 6, we have provided a template letter that a GP can complete which gives information on reasonable

Q&A

adjustments needed and whether the child can engage in physical activities. See **page 139**.

Assessing children's insight into their abilities should be done cautiously and with support from everyone who knows them. Allow children to judge for themselves how much they are able to do where possible. Believe them when they say they need to rest.

Some students will really want to go back to PE lessons because they enjoy it or attended clubs before their illness began. Even when they are signed off as able to do this we would again recommend a cautious and gradual approach – with shorter sessions and use of rest breaks as needed.

Remember that PESE can be experienced immediately, but also 24-72 hours after exertion.

What about break and lunchtimes?

An adjustment that might be quite common is to allow children to have one or two friends to sit and talk or play

quietly in a classroom over breaktime and lunchtime. Playgrounds and cafeterias are often very overwhelming from a sensory point of view. They may also require walking a fair distance to get to.

Some children may be using mobility aids (crutches, walkers, wheelchairs) depending on their energy level. Try to work the child and their parent to keep a symptom and energy diary to make sure that any activity increases don't worsen symptoms.

How will I recognise other Long Covid symptoms like PANS or PoTS etc?

Please see our guides in Section 2, **page 30**, which discuss these conditions and the common challenges children may present with.

Risk assessment

There may be additional risks that having Long Covid can bring and this will need to be risk assessed when a child returns to school or if their ability changes. Things that might need to be considered are:

- Safety to take part in Physical Education (see above)

- Risk of falls
- Evacuation plan for less mobile students
- Use of medication
- Impact of sensory loss or changes
- Impact on mental health and risk of self-harm or suicidal thoughts (make sure to speak to other staff that children come into contact with and keep each other informed of any warning signs)

What if a child needs more help?

Consider the use of IHPs and EHCPs as required.

What about recovery?

The concept of recovery is very individual – see docu Balance, Hope & Recovery on **page 84**.

Section 06

RESOURCES, LETTER & RECORD TEMPLATES

Cautious Tortoise

Managing Long Covid recovery for children



Cautious Tortoise
bit.ly/3CWsXFd

Cautious Tortoise

Cautious Tortoise was made by people living with Long Covid, for children and families living with Long Covid. It provides a practical step-by-step guide to supporting children who are recovering from COVID-19. It can be used by adults too.

The advice in this guide may reduce the potential impact of Long Covid. We don't yet have the longitudinal data or conclusive research that some clinicians would like to see before supporting this guide. However, the Long Covid conundrum is worldwide. We must learn from other post viral conditions and the weight of worldwide observational evidence including that which we have from our members. Our guide is supported by Long COVID Physio and Occupational Therapists For Long Covid.

Steps include:

- Provide every opportunity to allow plenty of rest and sleep.
- Seek medical support as often as you feel you need to, especially for new or worsening symptoms.
- Encourage fluids and good nutrition.
- Ask the question, "Is the child ready to do this?" at each step back to 'usual' life.
- Maintain open communication with your child, with school and with healthcare professionals.
- Remember recovery isn't linear – don't be afraid to take a step back at anytime if needed.
- Encourage slow, gradual and sustained changes.
- Pace activities and manage energy levels to support recovery.

CAUTIOUS TORTOISE



In Aesop's fable, the tortoise who keeps moving forward by taking slow and steady steps succeeds over the hare who races ahead. From what we know about conditions triggered by a virus, it is wise to take a cautious approach to recovery.

Watch for signs or symptoms that your child is not yet back to full health and modify activities accordingly. The Cautious Tortoise flowchart makes suggestions for identifying when it is appropriate to take the next step back to activities, guided by an adaptive pacing approach.



Pacing Penguins

Supporting kids with Long Covid to manage their energy

Brief summary of Pacing Penguins here.

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Pacing Penguins
bit.ly/3qk7H7e

128 longcovidkids.org

PACING PENGUINS



Penguins get their energy from fish. Activities they do depends on how many fish they have. Managing your energy is the same.

How to gain energy

Have a good night's sleep

Manage pain

Balanced diet/eat often

Drink enough water

Short frequent rests

Mindfulness/meditation

Leave some energy spare

Ask for help to do things

Use equipment to help

Do activities sitting down

Know what takes up energy

Medication to aid symptoms

Avoid overdoing it

Stabilise temperature

Sensible energy use

Plan your day/week/month

Be flexible/have a back-up plan

Break activities into small parts

Take mini-breaks in activities

Alternate easy/hard activities

Do what makes you happy

Learn what is most important

Rest before you need to

Spread your energy use out

Learn activity energy demands

Have regular quiet rest days

Balance brain and body energy

Use equipment/help as needed

Match activity to energy

Energy drains

Have a bad night's sleep

Staying up too late

Not eating enough

Making poor food choices

Not drinking enough

Issues going to the toilet

Side effects of medication

Doing too much or too little

Unmanaged symptoms

Anxiety and worry

Infection/illness

Being too hot or too cold

Extreme emotions

Unmanaged pain



LONG
COVID
KIDS



Recognition. Support. Recovery.
longcovidkids.org

Registered charity no: 1196170



Ask school for support letter template



Ask school for support letter template link here

Lots of parents on the Long Covid Kids Facebook support group tell us that they are finding it difficult to access school support and need help to enable school staff to fully understand the challenges of living with Long Covid and accessing education.

This is a template letter that you can individualise for your child's needs and circumstances and send to your child's

school to request a meeting to discuss the support arrangements your child will need.

The areas for personalisation are highlighted in the template for ease of reference. The highlight does not show when printed.

Travel assistance letter template



Travel assistance letter template link here

Short explanation about when to use this template and how to fill it in.

Teacher's Name Name of school Address line one Address line two Town or City / Postcode	Parent's Name Address line one Address line two Town or City Postcode
---	---

Date

Dear [class teacher, form tutor, SENCo or Head of Year]

As you know [child's name] is recovering from a COVID-19 infection. Following this, [he/she] [is/are] now experiencing a range of Long Covid symptoms [give details of child's circumstances, their ongoing symptoms, details of any professionals involved, details of any treatments/medications and details of any triggers which can worsen symptoms].

In order to ensure their continued inclusion and access to an education, I would like to meet with you and any other relevant staff to discuss the support arrangements [child's name] will now need.

In advance of the meeting, I am forwarding onto you the medical letters [if you have any, say who from and date of letter] regarding [child's name] which outline the difficulties [he/she] [is/are] facing and the adaptations suggested.

Given the symptoms and recommendations outlined above, I would suggest that [child's name] will need the following adaptations [make these individual to your child], but I am of course happy to discuss these in the meeting and to hear any suggestions you may also have:

- An extended and gradual phased return with a reduced timetable and time needed to attend medical appointments
- Access to remote lessons from home
- Increased flexibility around homework, tests and/or exams
- Extra time and rest breaks in exams
- Opportunities for rest and pacing during the day
- A quiet place to go at lunch and breaktimes
- An exit card to leave the classroom if feeling unwell
- Increased differentiation or non-attendance during PE lessons
- A keyworker such as an Emotional Literacy Support Assistant (ELSA), Emotional Mental Health Practitioner, Thrive practitioner or equivalent
- Additional opportunities for social interactions with peers or check-ins from staff
- An Individual Healthcare Plan

[Please also see more detailed support strategies in the LCK Teacher's pack that may be relevant to your child].

I am also forwarding onto you the Support Pack developed by www.longcovidkids.com, which gives more detail about Long Covid in children. It

also includes the Cautious Tortoise, Pacing Penguins, Tips for Teachers and Graduated Response guidance documents and the following government advice for children with medical needs which you may find helpful.

[Supporting pupils with medical conditions at school - GOV.UK \(www.gov.uk\)](http://www.gov.uk)


[Education for children with health needs who cannot attend school - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

Please let me know when might be a convenient time to meet.

Kind regards

[Name]

Parent of [child's name and class/form]



To whom it may concern

Long Covid Kids School Travel Assistance

Children and young people with Long Covid (also known as Post Covid Condition/Syndrome) experience a range of symptoms that affect their ability to do daily activities. In many cases Long Covid can be thought of as an energy limiting chronic illness. Many have remained unwell for over 12 months meaning that their condition is likely to fall under the protections of the Equality Act. Although we would urge the support outlined below to be implemented for those at any stage, particularly as we are aware that exacerbation in the acute stages of illness can lead to longer term difficulties.

One of the defining features of Long Covid is the experience of Post Exertional Symptom Exacerbation – whereby increasing activity levels (physical, cognitive, social or sensory) coincides with a worsening of each individual's symptom profile. Please note that sensory overstimulation (to noise, light, temperature) is common and this may preclude standard school transportation such as trains and buses.

As such, Long Covid Kids is promoting the use of extended and gradual phased returns to school and, in some cases, a permanent reduction to attendance timetables. This will leave some children and young people unable to attend full school days and means that they may have an increased need to travel at non-standard times.



Managing limited energy with a chronic illness demands a careful balancing act, and whilst these children and young people may on the outside appear to be physically capable of walking to school, the energy that this would use would then leave them unable to concentrate on their education. They would also be at risk of not being able to demonstrate, or fulfil, their academic potential. Some of these children may be ambulatory wheelchair users (this means they can walk at times, but that their ability to do so fluctuates and can cost them too much energy). Particularly when a child's journey to school takes a long time, they will need this journey to be as stress free as possible so that they arrive to school in a state of readiness to learn, and after a tiring day, have somewhere quiet to rest.

Recognition+Support+Recovery

Long Covid Kids
16 Blockmittle Field, Chesham,
Bucks, East Sussex, TN33 9AX

T: 07807 090 013
E: support@longcovidkids.org
longcovidkids.org

Registered charity no: 1198710



We would urge travel assistance teams to consider personal budgets, where appropriate, for these students and to review this provision regularly and flexibly. It may mean the difference between whether they are able to attend school face to face or not. Another key feature of Long Covid is its relapsing and remitting nature which means that support needs fluctuate over time.

Supporting the provision of taxis, or providing funding for parents to drop off and collect (where their employment or health status enables them to do this) would be two key adjustments that we would anticipate being helpful, and in some cases

If you need further information on this individual's symptom profile or needs please refer to any supporting medical evidence or consider supporting them to access review by health or social care professionals who are used to assessing those with complex chronic conditions (such as occupational or physiotherapists). Access to medical support for those with Long Covid has been patchy and sporadic so they may not have had the formal assessments necessary to provide the needed evidence.

We hope that this letter has provided you with useful supporting information. Please do visit our website for further guidance. This letter is provided as part of our Support and Recovery Pack.

Kirsty Stanley
Long Covid Kids Occupational Therapist


Long Covid Kids believe all children should be able to thrive and look forward to a positive future. That is why we represent and support children and young people living with Long Covid and related illnesses and the parents and caregivers that look after them.

Recognition+Support+Recovery

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Registered charity no: 1198710



LCK to GP letter template



LCK to GP letter template
link here

Short explanation about when to use this template and how to fill it in.

GP to school fitness and adjustments letter template



GP to school fitness and adjustments letter template
link here

Short explanation about when to use this template and how to fill it in.



Doctor's Name
Name of GP Practice
Address line one
Address line two
Town or City / Postcode

Date

Dear [GP Name]

Long Covid Kids is a registered charity that represents and supports children and young people living with Long Covid and related illnesses and the parents and caregivers that look after them.

[Child's Name] is a member of our Support Services and has been experiencing symptoms that could be considered as consistent with Long Covid.

[List Child's symptoms here]

If a child has been experiencing symptoms for 4 or more weeks they can be referred to a paediatrician and at 12 or more weeks they can be referred to one of 15 Paediatric Long Covid Hubs. Each hub will have its own referral criteria and they may request that certain blood tests and scans are completed before referral.

Please see the following guides for further consensus guidance.

[NICE guideline: COVID-19 rapid guideline: managing the long-term effects of COVID-19](#)

This guideline covers identifying, assessing and managing the long-term effects of COVID-19, often described as 'long COVID'. It makes recommendations about care in all healthcare settings for adults, children and young people who have new or ongoing symptoms 4 weeks or more after the start of acute COVID-19. It also includes advice on organising services for long COVID.


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Registered charity no: 1196370





[Recommendations for the recognition, diagnosis and management of Long Covid: A Delphi Study](#)

Although this document was written by and for adults it demonstrates a consensus agreement on a number of factors and guides assessment.

Research into children and young people is ongoing and is happening at pace. Parents are likely to be keeping up to date with what is happening so please meet them where they are and share resources.

Children with Long Covid are likely to need a period of rest and recovery and may need time off school or to have a slow phased return to school. We have written a second letter that you can complete as evidence for the school on fitness to attend and reasonable adjustments that are available.

As well as referral for medical investigations please could you support the family with accessing other services that will support them day to day, such as social services, occupational therapists, physiotherapists and other allied health professionals.

We hope that this letter has provided you with useful supporting information. Please do visit our [website](#) for further guidance. This letter is provided as part of our School Pack which contains information based on both lived experience and professional experience in supporting children and young people with long term health conditions, disabilities. We hope that this information is also useful to you. We will also be building up our resources for professionals and if there is any information you think it will be helpful for us to include do feel free to contact us.


Kirsty Stanley
Long Covid Kids Occupational Therapist

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Registered charity no: 1196370



Teacher's Name
Name of school
Address line one
Address line two
Town or City / Postcode

Date

Dear [class teacher, form tutor, SENCo or Head of Year]

I have assessed [name of student] on [dates] and they [have/have not yet] (delete as appropriate) been given a diagnosis of Post Covid Syndrome/Condition/Long Covid and [additional diagnoses].

The ongoing symptoms they are experiencing which will likely impact on their education are:

[list symptoms]

I can confirm that I [have/have not] screened for cardiac symptoms including POTS (using an active stand test).

I can confirm that I [have/have not] screened for oxygen desaturation on activity.

I can confirm that I [have/have not] screened for Post Exertional Symptom Exacerbation (PESE)/Post Exertional Malaise (PEM).

As a result of the screening above I confirm the following: (tick all that apply)

- They are not fit to engage in educational activity at home or school
- They are not fit to attend school but can engage in educational activity at home
- They may be fit to attend school with the reasonable adjustments highlighted below
- They are fit to attend school on a normal timetable
- They are not fit to engage in physical education
- They may be fit to engage in physical education with reasonable adjustments
- They are fit to engage in physical education

Reasonable adjustments proposed: (tick all that apply) (this list is not exhaustive)

- Hybrid learning options to include online and home learning
- An extended phased return starting at [number of hours/days] This needs to be maintained for [number of days/weeks] before increasing gradually
- A reduced timetable of no more than [number of hours/days] [maximum before review needed]
- Support with transport
- Frequent Rest Breaks
- An exit pass and quiet room in which to rest
- Exam/Coursework adjustments (add further detail below if specific adjustments requested)

Additional comments or advice:

- I will need to review them on [date]
- I will review them if they have not progressed as planned
- I do not need to review them

Signed

Date

Surgery stamp

LCK Padlet links