

Long Covid in Children - Impact of Long Covid on families.

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**LONG
COVID
KIDS**

About Long Covid Kids

- Grassroots organisation est Autumn 20
- **Registered charity Autumn 21**
- Connection, Advocacy & Signposting
- Improved health and learning outcomes
- Best possible treatment options
- **Real time research**

Each family we support has a child whose life has been turned upside down by Covid infection, **regardless of severity of acute disease, or the number of symptoms.**

Long Covid from 1st /2nd /3rd / 4th infections

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11,000

World Health Organisation Europe



Meet Kitty McFarland, my daughter.
(proud Mum)

Kitty is supporting the World Health Organisation with their campaign to raise awareness of Long Covid in CYP

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

WHO/Europe calls for research and recognition of long COVID, as well as rehabilitation for people living with the condition.

Personal Experience of Long Covid

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Long Covid and My Family

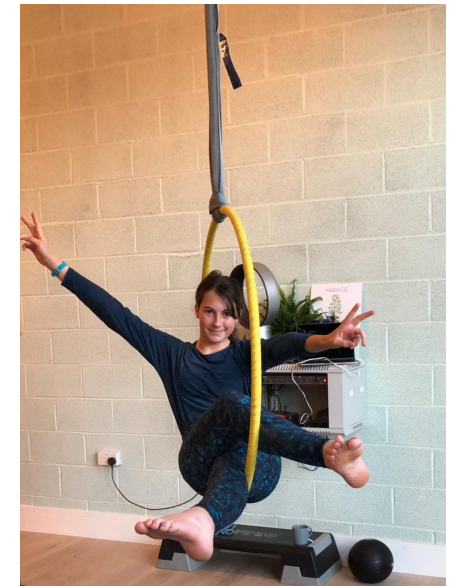
Prior to COVID:

Kitty, Age 14 was a ballerina just being measured for her pointe shoes.

She enjoyed aerial trapeze, running, paddleboarding, surfing and being outside.

Fit and healthy, no underlying health conditions, an active role in the community.

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Covid-19 Infection

Acute Covid

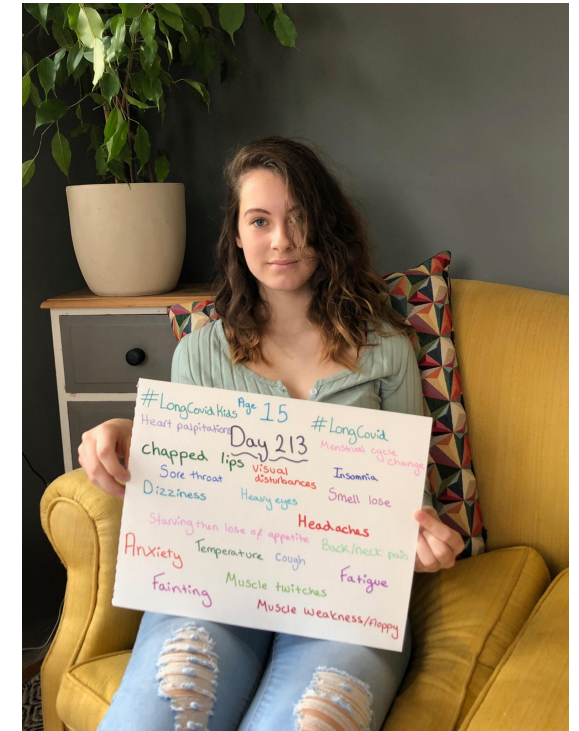
- Kitty contracted COVID 10 days after me, March 2020.
- Neither of us were hospitalised
- Before vaccinations
- Kitty - Cough, low grade fever, chills, cough, sniffy, floppy, fatigue
- She felt fine after 10 days, just a bit tired.

Post Covid

- Kitty deteriorated after 5-6 weeks with new symptoms: chest pain, abdo pain, gastro issues, heart palpitations, tachycardia, dizziness, extreme fatigue, tinnitus, low mood, insomnia.
- No medical appointments offered. Nurse said ‘probably just mimicking my symptoms/missing friends
- Since diagnosed with Long Covid: Dysautonomia, Ovarian Cysts, Vasovagal Syncope, Anemia, PoTS
- Undiagnosed suspected: Coeliac, MCAS
- **37 months on** – dizziness, abdo pain, heart palpitations, tinnitus, auditory sensitivity, temperature dysregulation, extreme sweating, changes to her vision, extreme exhaustion..

Access to Healthcare and Ongoing Treatment

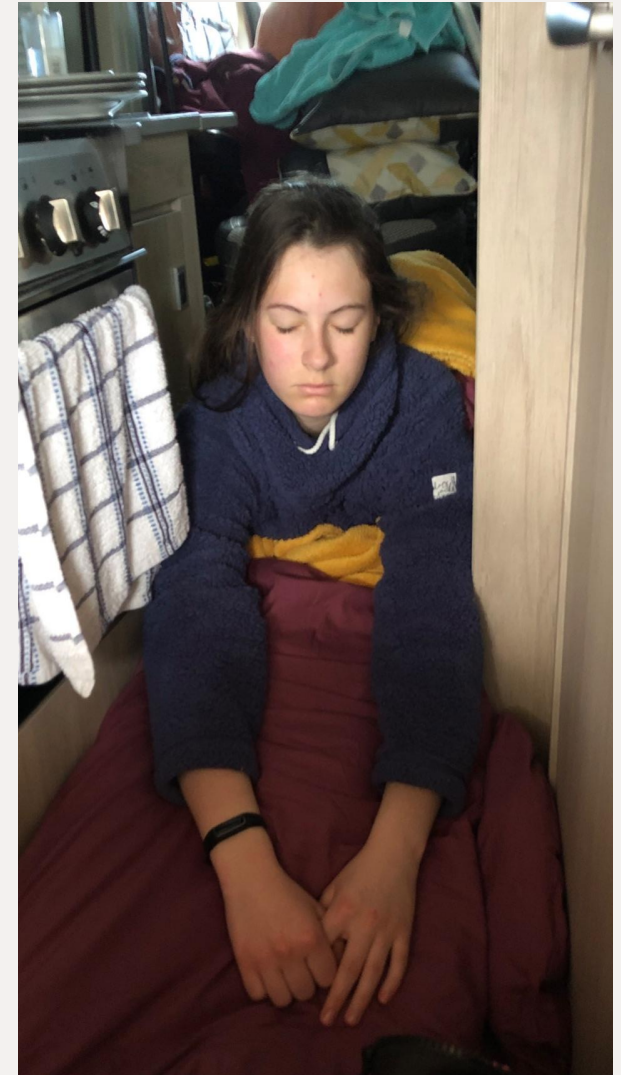
- Long wait to see a Paediatrician / NHS Cardiologist, frequently cancelled appointments, 3 different paediatricians in 3 different appointments. Telephone / zoom calls from the C fatigue service after 18 mths.
- Online assessment for the Long Covid clinic. Focus on managing symptoms. Referral to CAMHS and for a abdominal ultrasound. No treatment. No process for review.
- Private Consultations - Naturopath, Paediatrician, Cardiologist, Hematologist, Osteopath, Clinical Reflexologist.
- Probiotics, vitamins and minerals, electrolytes, iron infusions, antihistamines, anti sickness medication heart medication, pacing and PoTs protocols.



Impact Upon Daily Life and Family

Huge impact on quality of life, now unrecognisable:

- Unable to access mainstream education / self belief
- Most days she was physically unable to attend school
- Slept most of every day/night for over 20 months
- Missed out on seeing friends, hobbies and social events
- Unable to return to any of her previous activities - she had started short walks before a recent reinfection/new symptoms....
- Wider impact - household finances, appointments / work hours, relationships, daily life, holidays, friendships



Long Covid Support and Long Covid Kids published the first data on the effect of COVID reinfections on adults and children living with Long Covid. Further information can be found in our blog.

<https://www.longcovidkids.org/post/a-world-first-effect-of-covid-reinfection-on-people-living-with-long-covid>

Reinfection worsens
the symptoms of
Long Covid
in the majority of children
who are still symptomatic



Reinfections in Long Covid Survey Aug 2022
Long Covid Support / Long Covid Kids

Reinfection causes a
recurrence of Long Covid in
58% of children who were in
recovery or remission.

This is similar to all respondents including adults



Reinfections in Long Covid Survey Aug 2022
Long Covid Support / Long Covid Kids

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82% of child respondents first
got Long Covid after their 1st
infection
17% after their 2nd infection and
1% after their 3rd infection

This is similar to all respondents including adults.



Reinfections in Long Covid Survey Aug 2022
Long Covid Support / Long Covid Kids

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Government/Policy Makers

- Poor knowledge/awareness of lived experience
- Absence of paediatric Long Covid clinical definition
- Absence of accurate Long Covid data recording
- Inaccurate reporting of new research & COVID19 harm
- Inaccurate narrative of harms to children & young people.

Healthcare

- Absence of paediatric Long Covid training and support for NHS healthcare professionals
- Absence of high-quality biomedical paediatric research
- Dismissal & minimising of symptoms
- Specialist care waiting times
- Lack of treatment options
- Misdiagnoses

Education

- Absence of paediatric Long Covid training and support for educators and school staff
- Difficulty accessing flexible and/or hybrid learning options
- Insufficient ASN/SEN services
- Access to school transportation

Physical

- Significant symptom burden
- Practical challenges in accessing education
- Inability to enjoy hobbies
- New onset mobility issues
- Pain

Mental Health

- Feeling isolated & unsupported
- New onset altered mental health from organic causes and/or impact of experience
- Absence of paediatric Long Covid training and support for CAMHS healthcare professionals
- Extensive waiting lists to access mental health services

Effects on the Family

- Employment absence
- Childcare challenges
- Financial burden
- Mental & physical health burden
- Sibling relationships & emotional health
- Isolated & unsupported
- Impact on social relationships



**LIZ,
AGE 16**



It's also emotionally draining because I find it incredibly hard to interact with other people my age, even friends I had before I got ill.

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Signposting Resources and References

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Long Covid Kids Resources



Impact Report - Key Publications

<https://www.calameo.com/brand-and-soul/read/000561176f300f1560c2e?page=1>

Support Guide

<https://www.calameo.com/brand-and-soul/read/0005611766a955a557db0?view=book&page=1>

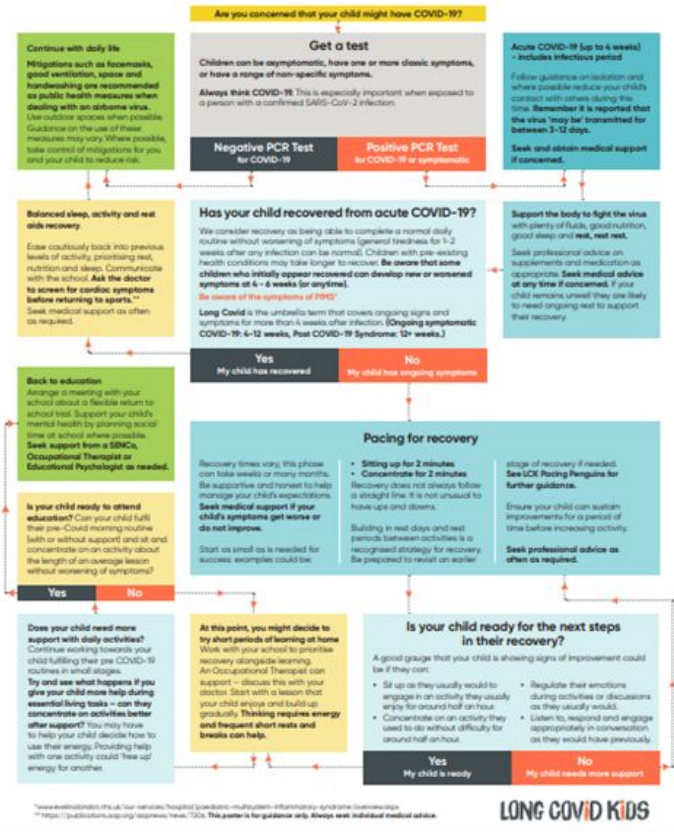
Early Intervention & Support

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



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

Support the body to fight the virus with plenty of fluids, good nutrition, good sleep and rest, rest rest.

- Seek professional advice on supplements and medication as appropriate. Seek medical advice at any time if concerned, if your child remains unwell they are likely to need ongoing rest to support their recovery.

Recovery times vary, this phase can take weeks or many months. Be supportive and honest to help manage your child's expectations. Seek medical support if your child's symptoms get worse or do not improve.

- Start as small as is needed for success: examples could be:
 - Sitting up for 2 minutes
 - Concentrate for 2 minutes
- Recovery does not always follow a straight line. It is not unusual to have ups and downs.
- Building in rest days and rest periods between activities is a recognised strategy for recovery. Be prepared to revisit on another stage of recovery if needed. See Pacing Penguins for further guidance.
- Ensure your child can sustain improvements for a period of time before increasing activity. Seek professional advice as often as required.

Recognition. Support. Recovery.
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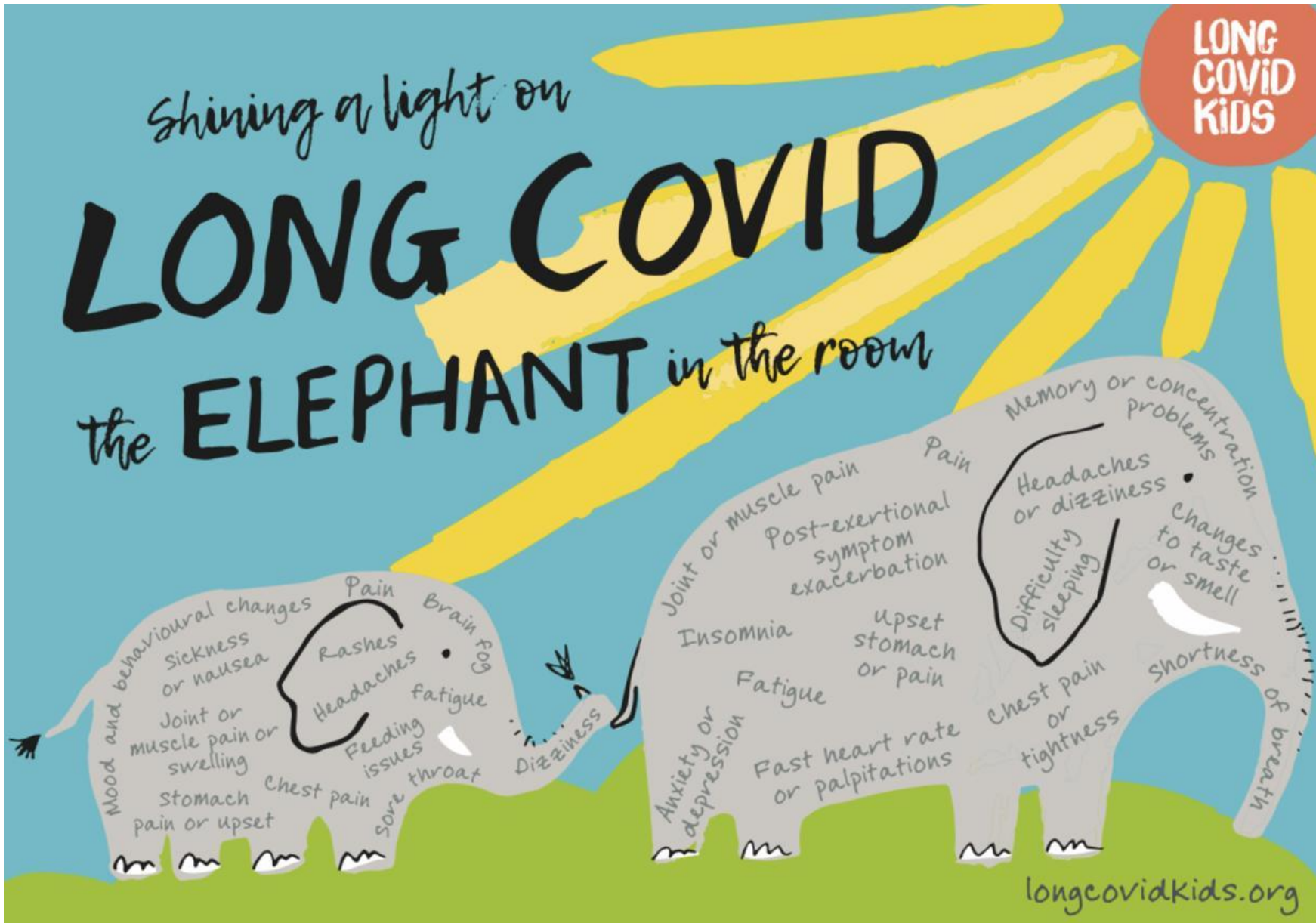
Registered charity no: 116170
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Cautious Tortoise

<https://www.longcovidkids.org/post/long-covid-recovery-for-children-cautious-tortoise>

Pacing Penguins

<https://www.longcovidkids.org/post/pacing-penguins-supporting-kids-living-with-long-covid-to-manage-their-energy>



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Shining a light on
LONG COVID
the **ELEPHANT** in the room

Please sign up to our newsletter via our website to stay in touch.

<https://www.longcovidkids.org/>



info@longcovidkids.org



[@LongCovidKids](https://twitter.com/LongCovidKids)

Thank you.

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