

# LONG COVID IN SCHOOLS AND COLLEGES

---

**Dr Olly Jefferis**

Consultant paediatrician, Oxford University Hospitals

**Gemma North**

Specialist physiotherapist, Oxford University Hospitals

**Amanda Neophytou**

Specialist occupational therapist, Oxford University Hospitals and Oxfordshire ME/CFS service

**Dr Konrad Jacobs**

Consultant Clinical Psychologist, Oxford University Hospitals

**Steve Lowe**

Headteacher, Oxfordshire Hospital Schools, Director of the National Association of Hospital Education

16.00	Introduction	
16.02	HealthTalk video	
16.05	Medical aspects of LC	<i>Dr Olly Jefferis</i>
16.15	Occupational therapy	<i>Amanda Neophytou</i>
	Physiotherapy	<i>Gemma North</i>
16.30	Clinical Psychology	<i>Dr Konrad Jacobs</i>
16.40	Medical Needs in Schools	<i>Steve Lowe</i>
16.45	Resources	
16.46	Q & A	<i>Dr Emma Dunford</i>

# HealthTalk

## Family experiences of Long Covid

---

<https://healthtalk.org/Family-experiences-of-Long-Covid/overview>

# School and Long Covid



# Consultant paediatrician

Dr Olly Jefferis

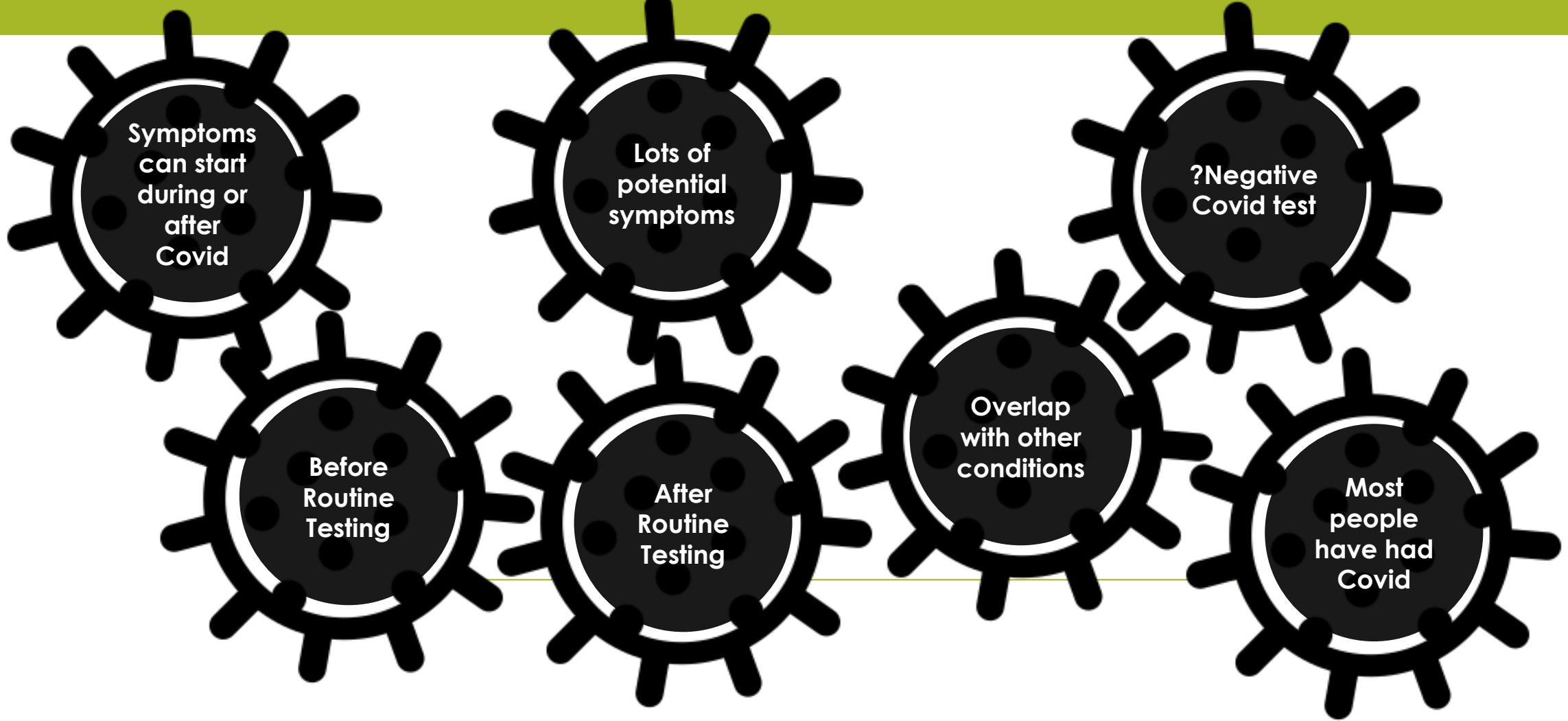
# WHAT IS LONG COVID?

---

# Definition

## Post COVID Syndrome (NICE)

- 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.
- In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).



What is Long Covid?

Not always clear-cut



# What is long covid?

---

Persistent symptoms following a COVID infection

---

Occurs even if initial infection was mild

---

Over 200 symptoms reported and can affect any organ system

---

For some it can be very debilitating

# How common is it?

- Estimated 1.9 million people in the UK (2.9% of the population) symptoms more than 4 weeks Post COVID
- Estimated 62 000 children aged 2- 16 years
- 1% of 12-16 year olds
- 0.3% of 2-11 year olds
- Estimated 53 000 2- 16 year olds with symptoms for at least a year
- Estimated 10 000 children aged 2- 16 years reporting “A lot” of activity limitation

# Potential Risk factors for long covid



Oxford University Hospitals  
NHS Foundation Trust

---

Female sex

---

Type 2 diabetes

---

EBV reactivation

---

Presence of specific autoantibodies

---

Connective tissue disorders

---

Attention deficit hyperactivity disorder

---

Chronic urticaria

---

Allergic rhinitis

---

Pre-COVID self-reported physical and mental health

---

Autistic Spectrum Condition

---

Davis, H.E., McCorkell, L., Vogel, J.M. and Topol, E.J., 2023. Long COVID: major findings, mechanisms and recommendations. *Nature Reviews Microbiology*, pp.1-14.

Nugawela, M., Stephenson, T., Shafran, R., De Stavola, B.L., Ladhani, S., Simmons, R., McOwatt, K., Rojas, N., Cheung, E.Y., Ford, T. and Heyman, I., 2022. Developing a model for predicting impairing physical symptoms in children 3 months after a SARS-CoV-2 PCR-test: The CLoCk Study. medRxiv.

# What causes long covid?

Consequence of severe disease

Autoimmunity

Persistent low-level inflammation (viral persistence or viral debris)

Covid-induced neurological damage (eg autonomic nervous system)

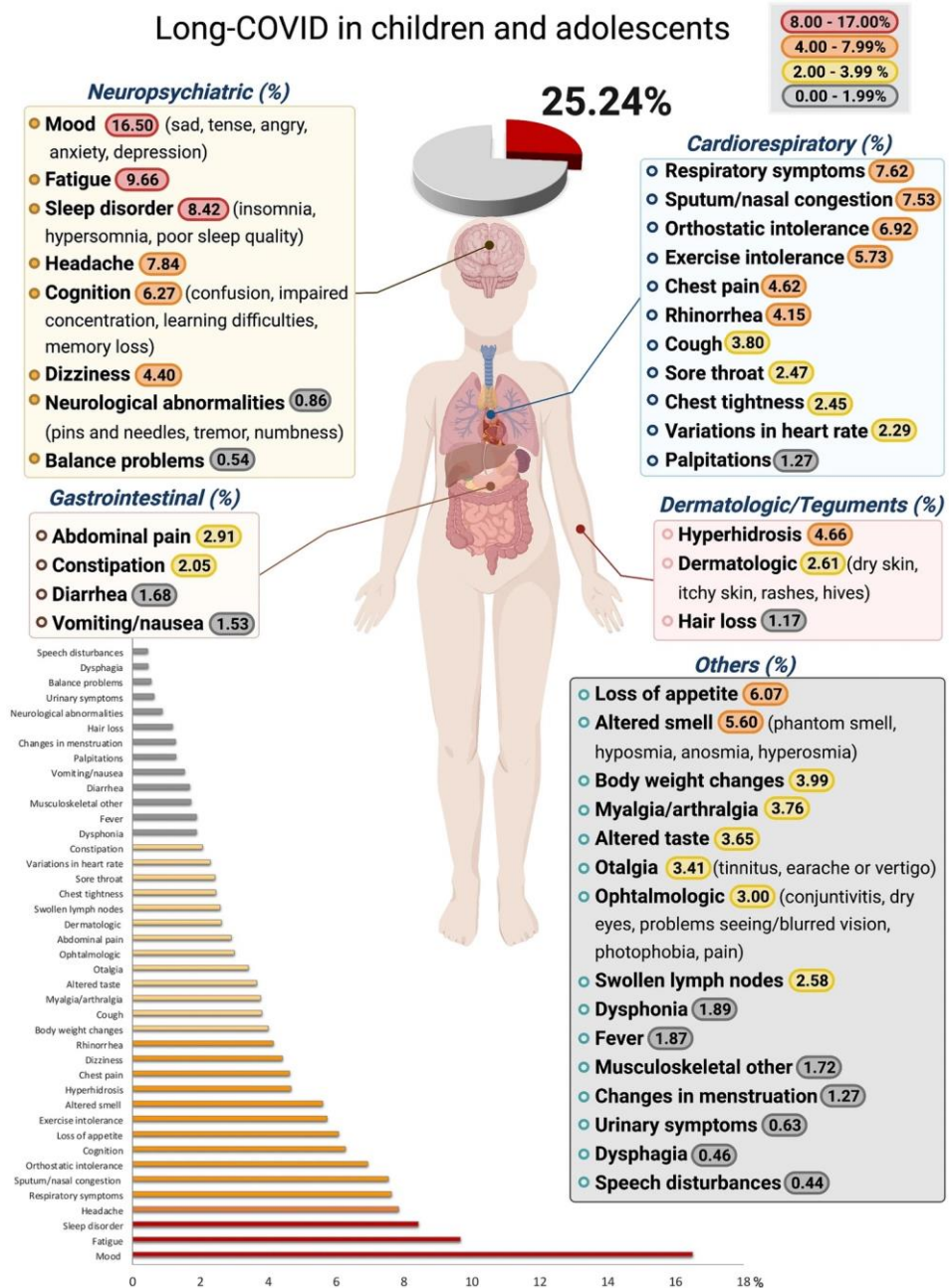
Multi-organ damage (eg microclots)

Something else

# COMMON SYMPTOMS

---

# Long-COVID in children and adolescents



Lopez-Leon, S., Wegman-Ostrosky, T., Ayuzo del Valle, N.C., Perelman, C., Sepulveda, R., Rebolledo, P.A., Cuapio, A. and Villapol, S., 2022. Long-COVID in children and adolescents: A systematic review and meta-analyses. *Scientific Reports*, 12(1), p.9950.

# Presenting symptoms



Fatigue  
93%



Respiratory  
21%



Pain  
46%



Abdominal  
pain  
22%



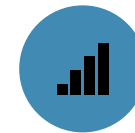
Brain fog  
17%



Headaches  
33%



Anxiety/low  
mood  
28%



Other  
25%

# Medical input

Making sure there is not another diagnosis

Complete investigations

Identify treatable traits

Liaising with other medical teams

Be aware of new research and treatments

Ongoing input to MDT



# Management of symptoms

Fatigue/Energy  
management

Sleep

Chronic Pain

Breathlessness

Postural  
Symptoms

Taste and  
Smell issues

Mood / Anxiety

Autism  
Spectrum  
Disorder

Rehabilitation

# What about other treatments?

Lots of tantalising  
media reports

Nothing yet with  
sufficient  
evidence to use in  
clinical practice

Frustration for  
patients, families  
and clinicians



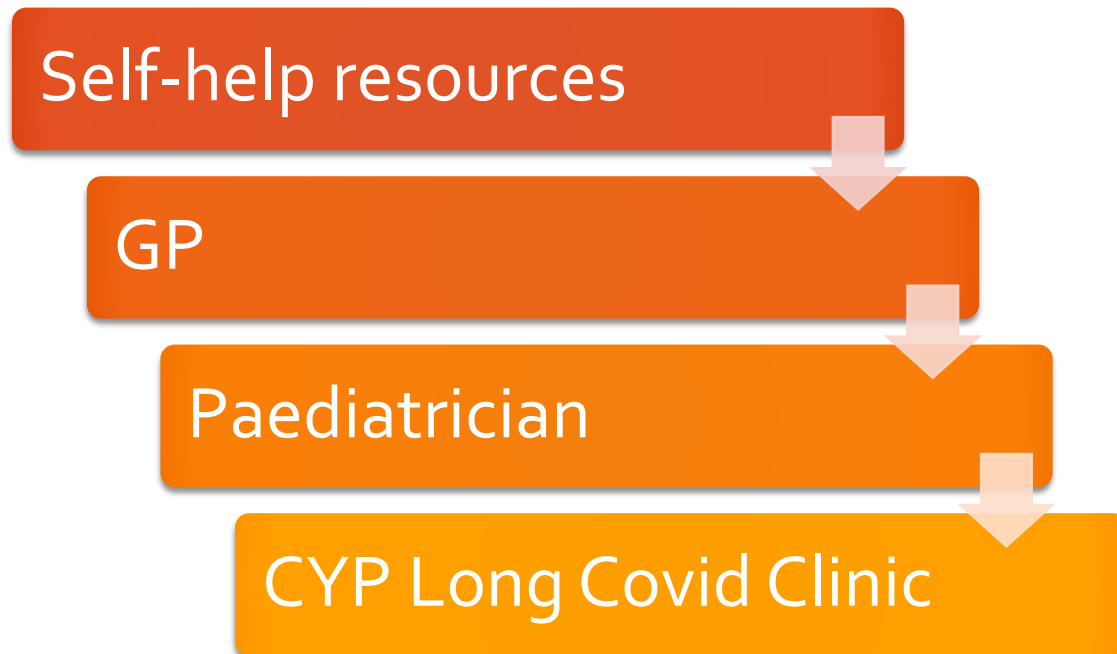
Oxford University Hospitals  
NHS Foundation Trust

# PATHWAYS FOR REFERRAL

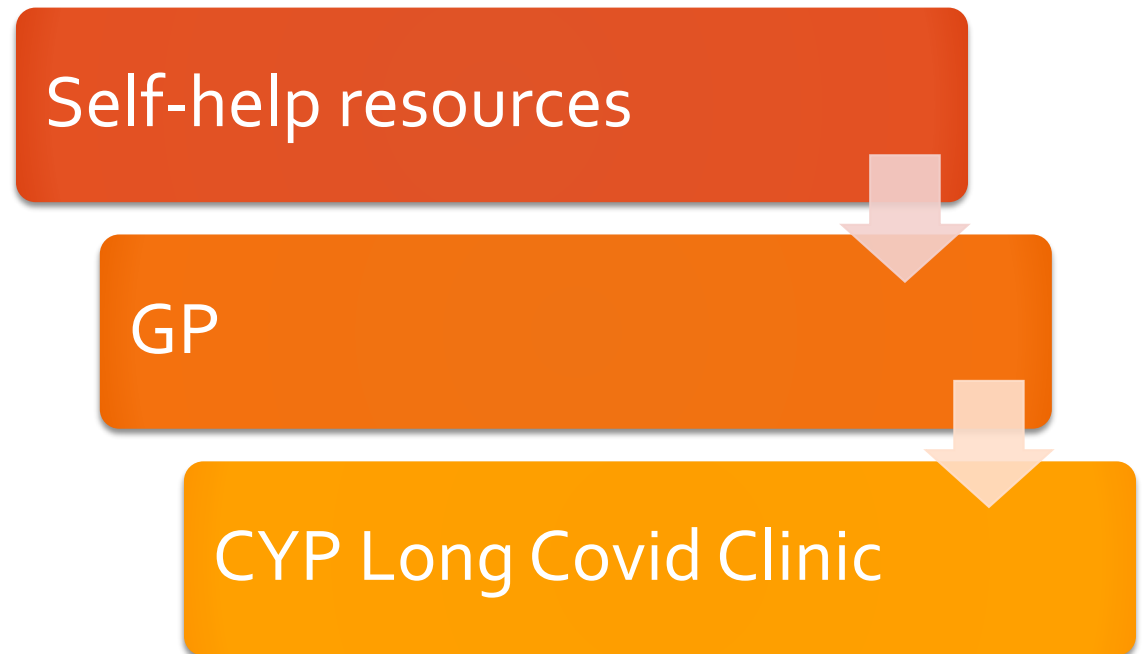
---

# Pathways of referral

## Under 16 years



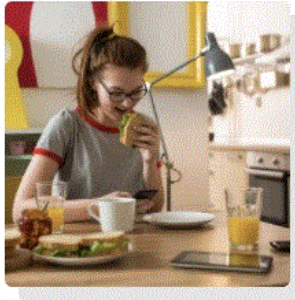
## Over 16 years



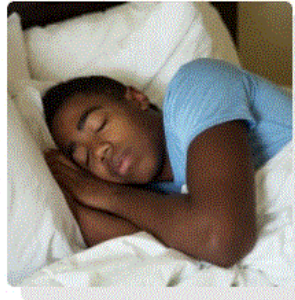
# Self-help resource



**Managing daily activities**



**Eating well**



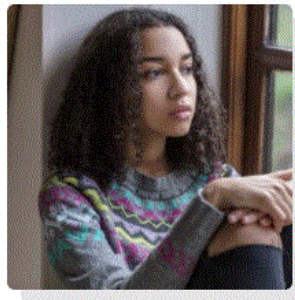
**Sleeping well**



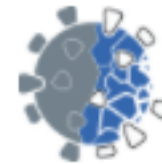
**Returning to education for pupils and students**



**Returning to education for parents and carers**



**Managing emotions and feelings**



Your  
**COVID Recovery**



# Self-help resource- Long Covid kids



## 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.



\*[www.oxfordhospitals.uk/our-services/hospital/paediatric-multi-system-inflammatory-syndrome/overview.aspx](https://www.oxfordhospitals.uk/our-services/hospital/paediatric-multi-system-inflammatory-syndrome/overview.aspx)  
\*\*<https://publications.nhs.uk/topics/news/7205>. This poster is for guidance only. Always seek individual medical advice.



Oxford University Hospitals  
NHS Foundation Trust

# Research studies

- STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways)
- LOCOMOTION (long COVID multidisciplinary consortium: optimising treatments and services across the NHS) study
- EXPLAIN (Hyperpolarised xenon magnetic resonance pulmonary imaging in patients with Long-COVID)
- CICERO (Cognitive Impairment in long COVID: PhEnotyping and RehabilitatiOn)
- LISTEN (Long COVID Personalised Self-management support - co-design and EvaluatiON)
- ReDIRECT: Remote Diet Intervention to Reduce long Covid symptoms Trial
- The immunologic and virologic determinants of long COVID
- Quality-of-life in patients with long COVID: harnessing the scale of big data to quantify the health and economic costs
- Percutaneous Auricular Nerve Stimulation for Treating Post-COVID Fatigue (PAuSing-Post-COVID Fatigue)



Oxford University Hospitals  
NHS Foundation Trust

# Research studies

- Percutaneous Auricular Nerve Stimulation for Treating Post-COVID Fatigue (PAuSing-Post-COVID Fatigue)
- Immune analysis of long COVID to inform rational choices in diagnostic testing and therapeutics
- Understanding and using family experiences of managing long COVID to support self care and timely access to services
- Development of a robust T cell assay to retrospectively diagnose SARS-CoV-2 infection and assays as diagnostic and monitoring tools in long COVID patients
- Using Activity Tracking and Just-In-Time Messaging to Improve Adaptive Pacing: A Pragmatic Randomised Control Trial
- Impact of COVID-19 vaccination on preventing long COVID: a population-based cohort study using linked NHS data
- Long COVID Core Outcome Set (LC-COS) project

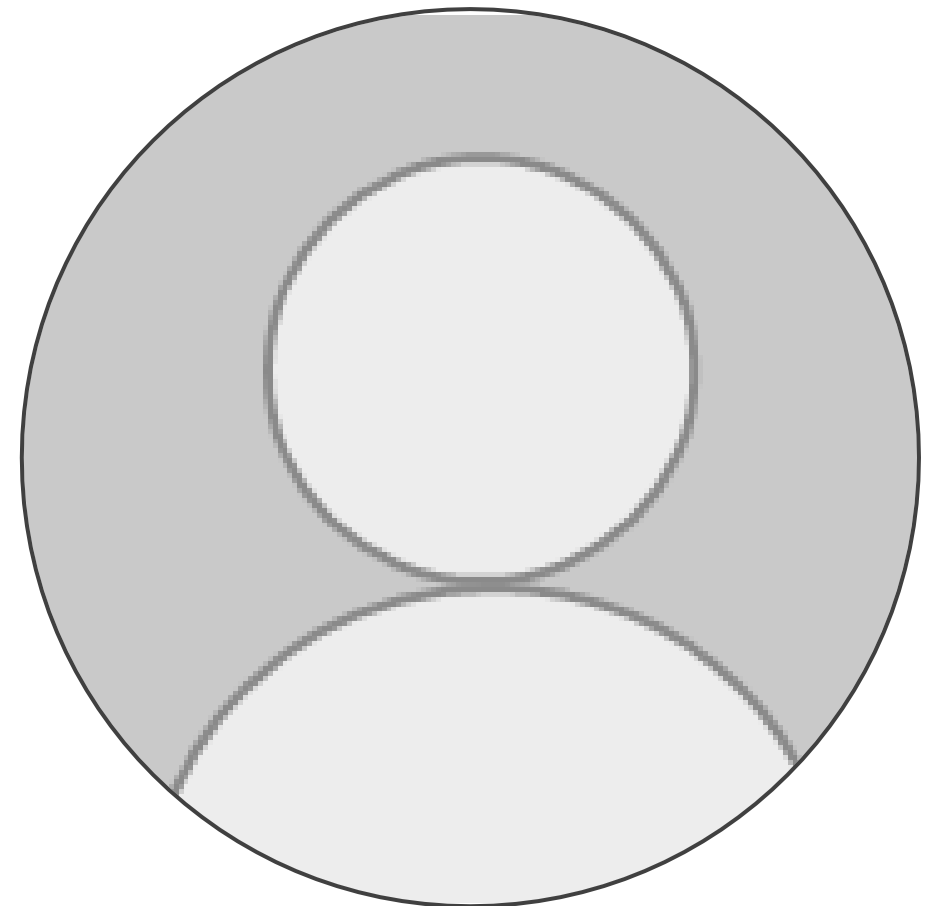


# Occupational therapist

Amanda Neophytou

# Physiotherapist

Gemma North



# Children's and Parents' views

## 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.**



Learn more:  
[bit.ly/3EtdhdV](https://bit.ly/3EtdhdV)

[longcovidkids.org](https://longcovidkids.org) 07

Life as a young person with long COVID: "You go through so many phases of up and down, it's like being on a rollercoaster forever"

**What children want their teacher to know**

We asked children via their parents/carers in our Support Services to highlight 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.
- 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 MAY BE A BIT BETTER ONE DAY, OR WORSE ANOTHER, OR A WEEK LATER.
- I AM WORRIED THAT YOU DON'T BELIEVE I AM SICK. I MAY SEEM OK, BUT THEN I AM NOT.
- 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.

98 longcovidkids.org 99 longcovidkids.org

"There is not a one-size-fits-all approach to supporting children and young people in the classroom"

[British Journal of Child Health - Supporting children and young people with long COVID in the classroom](#)

Images by Long Covid kids

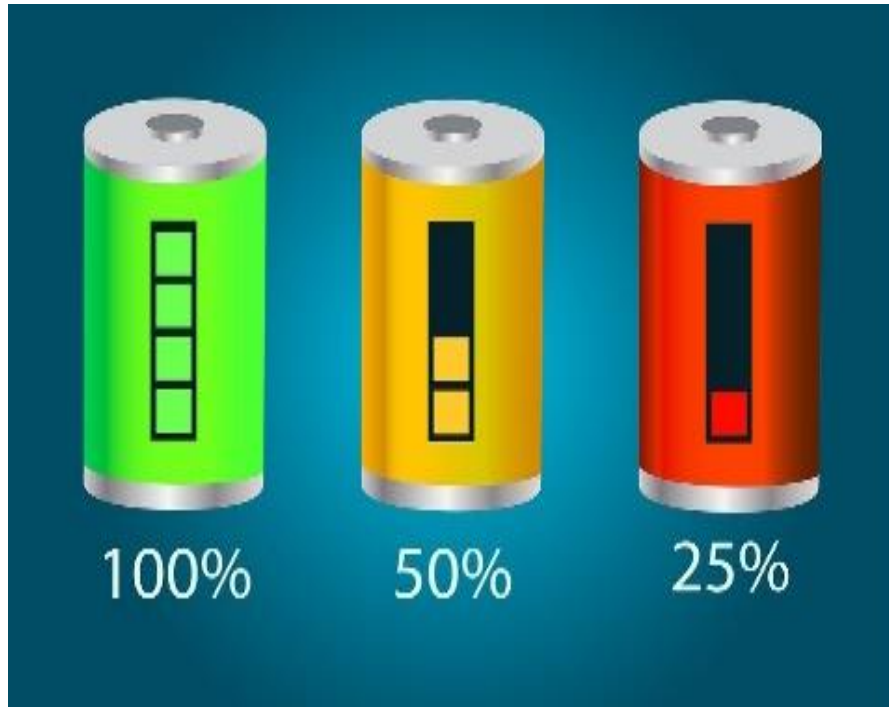
# Symptom management

(strategies to support fatigue, brain fog, joint pain, POTs etc)

- Support to adapt to changes in ability due to their long term condition and enabling them to find new ways to engage in meaningful activities.
- Awareness of the impact of physical, cognitive, social and emotional energy.
- Introducing principles of planning, pacing and prioritising
- Regulate sleep pattern
- Baseline- balance between over-activity and underactivity
- Avoid the 'boom and bust' cycle.
- Managing setbacks.....
- Physiotherapy exercises – POTs, keeping mobile, strong and flexible, not GET
- Awareness of postures, environments, tasks and their impact
- Other - medication, eating and drinking



# The human battery...



Recognising your current battery level

The human battery works on supply and demand.

Energy in – energy out.

Keep some reserves (avoid boom and bust)

There are a number of ways to improve the supply, manage the demand and keep it healthy

# Balance of Energy/Activity

Being 'slow and steady'

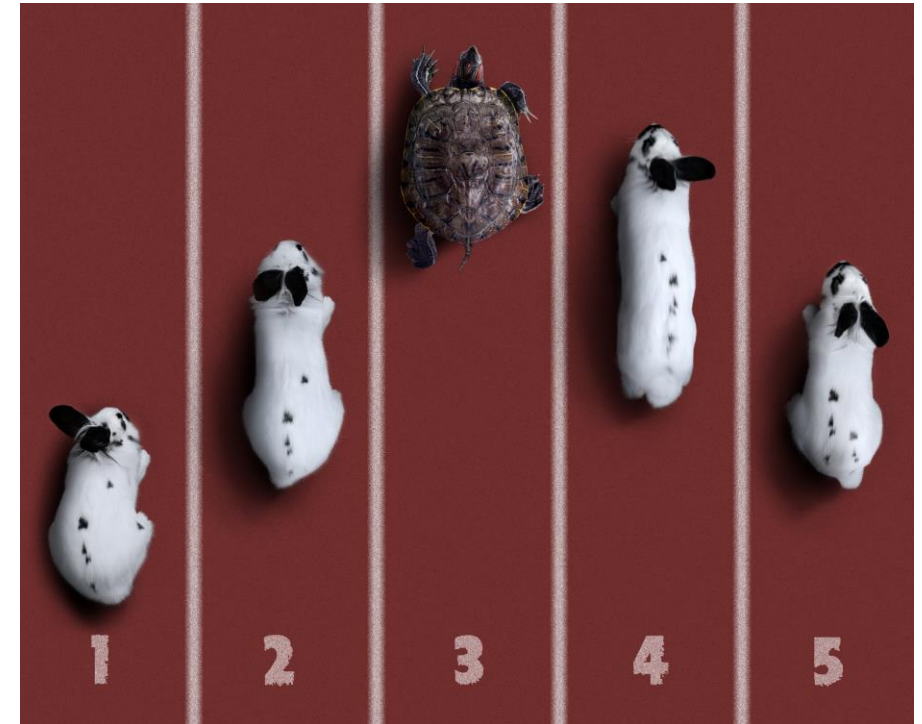
Pacing- setting limits, breaking down tasks  
'chunking'

Balance of activity each day– physical and  
cognitive

Regular rest and re-charge (bridge analogy)

Use of activity diaries, energy requirements-  
high, med, low

Do things you enjoy and help to energise....





# Accessing Education

- Blended or independent learning, e.g. online/tuition
- Gradual return to school/college.
- Key/trusted person in school for regular contact
- Reduced timetable and subjects
- Later start or early finish
- Extended homework deadlines/support with exams
- Quiet area/room to study and rest/re charge
- Time-out card
- Include social time and break/lunchtime
- Physical aspects - travel/walking/stairs, PE, Sensory overload- light/noise



**Case study:**

16yr old male, whole family ill in Feb' 20, initial symptoms: high temp, fatigue, breathlessness

**LC symptoms:**

fatigue, poor concentration, headaches, muscle and joint pain, poor sleep, nausea and gastric pain, blurred vision

Problem	Strategy
<u>Sleep</u> up to 2 hrs to get to sleep, then wakes in the night, not rested	Melatonin, evening routine (screens), regular sleep/wake time
<u>School</u> GCSE yr 11- flexible part-time timetable, irregular attendance, dropped some subjects	Mtg with school, reduced timetable and rest breaks, extended deadlines, exam adjustments
<u>Activity</u> occasional bike ride, Airsoft (up to 4 hrs), video games with friends	Goal setting and Pacing, physio stretches + exercise plan eg 2 mins rowing daily, not currently doing PE
<u>Wellbeing</u> worry re: what people think, understanding of fatigue, not seeing friends	Info on fatigue/LC , emphasis on enjoyable activity/social time, include lunch etc in school plan
<u>Diet</u> limited diet + poor hydration	Diet info, grazing, water bottle

# Clinical Psychology

Dr Konrad Jacobs



# The psychological effects of the COVID-19 pandemic

- Most studies reported longitudinal deterioration in the mental health of adolescents and young people, with *increased depression, anxiety and psychological distress* after the pandemic started. Other findings included deteriorated *negative affect, mental well-being and increased loneliness*.
- Among the most important issues are the irreparable effects of *losing a parent or the death of a loved one* due to this disease (loss and grief) and a wide range of other disorders, such as feelings of *fear, anxiety, depression, sleep problems, and post-traumatic stress disorder*.....the effects of prolonged school closures and turning to social media without parental supervision and adequate infrastructure for children cannot be ignored.
- *A large increase in the number of hospitalizations and an increase in eating disorder symptoms, anxiety, depression*.....Many qualitative studies described this was due to *decreased access to care and treatment, changes to routine and loss of structure, negative influence of the media, and social isolation*.
- However, one-third (33%) of CYP (17.00 UK school children between 8-18) reported improved mental wellbeing during the first UK national lockdown. They reported improved relationships with friends and family, less loneliness and exclusion, reduced bullying, better management of school tasks, and more sleep and exercise during lockdown.

Kauhanen, L., Wan Mohd Yunus, W., Lempinen, L. *et al.* A systematic review of the mental health changes of children and young people before and during the COVID-19 pandemic. *Eur Child Adolesc Psychiatry* (2022).

Nafei Z, Samadzadeh G, Ordooei M, Vaghefi M. Psychological Impact of COVID-19 on Children and Adolescents: A Narrative Review. *Journal of Pediatrics Review*. 2023; 11(1):67-76

J Devoe D, Han A, Anderson A, Katzman DK, Patten SB, Soumbasis A, Flanagan J, Paslakis G, Vyver E, Marcoux G, Dimitropoulos G. The impact of the COVID-19 pandemic on eating disorders: A systematic review. *Int J Eat Disord*. 2023 Jan;56(1):5-25.

Soneson, E., Puntis, S., Chapman, N. *et al.* Happier during lockdown: a descriptive analysis of self-reported wellbeing in 17,000 UK school students during Covid-19 lockdown. *Eur Child Adolesc Psychiatry* (2022).

# The educational effects of the COVID-19 pandemic

- The studies reviewed imply that the significant disruption in children's education as a result of school closure during the COVID-19 pandemic has been problematic and has resulted in learning losses.

Spiteri, Deguara, Muscat, Bonello, Farrugia, Milton, Gatt & Said (2023) The impact of COVID-19 on children's learning: a rapid review. *Educational and Developmental Psychologist*, 40:1, 5-17,

# Factors in long COVID that impact on education:

- Memory and concentration deficits
- “Brain fog”
- Executive functioning
- Excessive fatigue
- Headaches / musculoskeletal pain
- Anxiety
- Depression
- Autism – Possibly around 1/3!

These effects are *cumulative*, often *inter-related* and these effects are *REAL*

# Fluctuations in activity / energy

- Fluctuations in symptoms are normal
- And are NOT signs of malingering
- But instead are related to fluctuations in activity levels, sleep, mood and feelings

# Relationship between physical symptoms and psychological functioning

- If you have physical symptoms *and* psychological problems, the situation is more difficult and overwhelming, less easy to solve; as physical symptoms cannot easily be solved, mental health could become a target
- High levels of stress → high 'autonomic arousal' (fight or flight)  
→ more tired / more pain
- Depression → low motivation / tendency to withdraw  
→ does not help rehabilitation / can make physical functioning and sleep worse
- Young people with high anxiety tend to be more threat-oriented, also in relation to physical symptoms

# Parents / carers

- The LARGE MAJORITY of parents do their best in difficult circumstances
- Often feel that their child's symptoms are not taken seriously
- Often do not know whether to encourage to participate or to reduce activity levels. They tend to do the latter in the absence of information

Need to engage with them seriously, but also need to discuss with other agencies if no progress is made despite maximum effort

# Management in education 1

- ENGAGEMENT! The family and child need trust before anything else – this will save time in the long term
- Being empathetic and explicit in conveying belief in the reality of the *experience* of physical symptoms
- Who does the child like and trust at school?
- Shift focus from 'cause' to 'symptom management'
- Reduction in anxiety levels – what are the factors that increase the threat level at school and how can they be mitigated?
- Normalising symptoms – “there are other pupils at this school with the same problem”

# Management in education 2

- Close contact with medical & rehab teams / GP to avoid 'splitting'; set up professionals meeting?
- Many parents will feel they and their child have not been taken seriously – they are protecting their child
- Weary school response <> parents respond
- Try to avoid stand-offs
- What are the barriers? Look beyond physical symptoms (sensory issues, specific LDs, ASD, mental health)



# SUPPORTING PUPILS AT SCHOOL WITH MEDICAL CONDITIONS

---

## Medical Needs in Schools Project



**Highfield Hospital Inpatients** 



 **Children's Hospital Teaching Service**

 **Outreach Teaching Service**



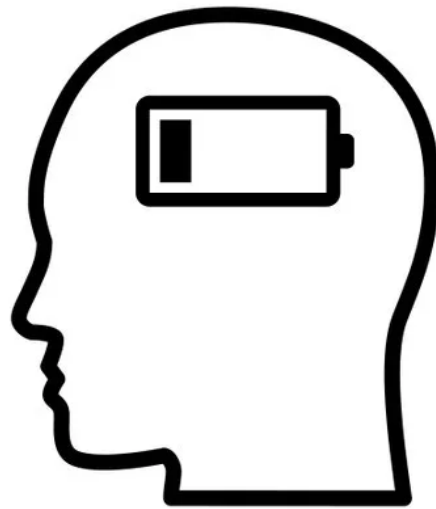
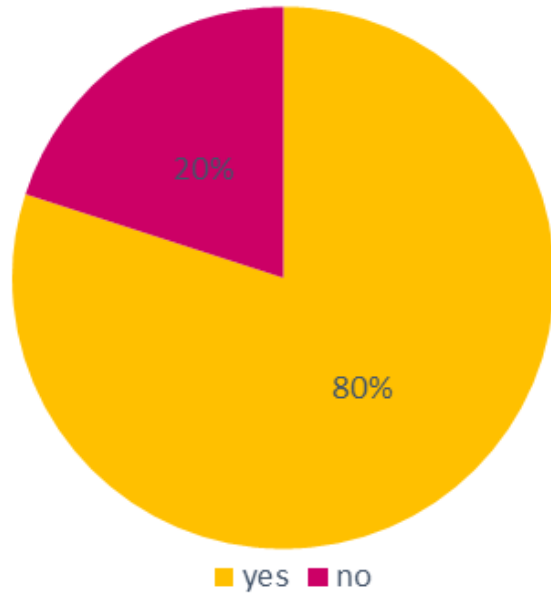
<https://ohs.oxon.sch.uk/>  
01865 957480  
[office@ohs.oxon.sch.uk](mailto:office@ohs.oxon.sch.uk)  
School: @OxHospSchool



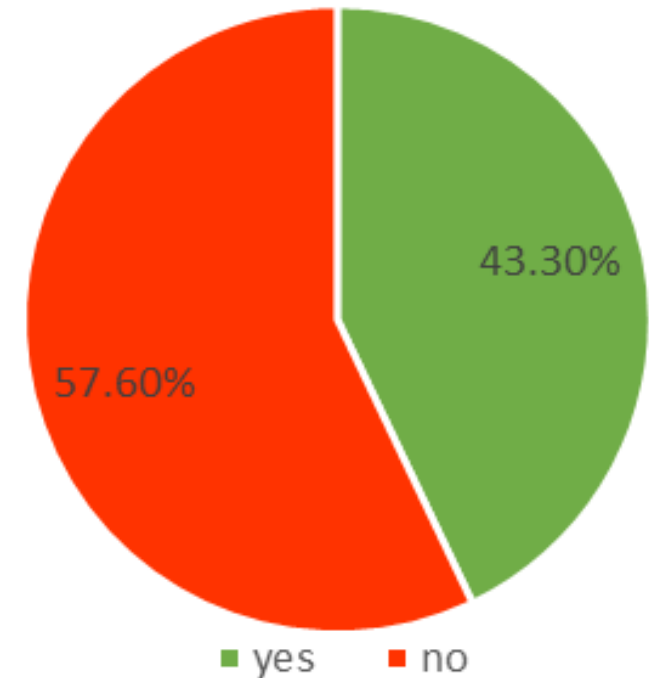
# Education Health & Care Plans - EHCPs

A study of more than 1500 CYP  
with Chronic Fatigue

Impacted for more than 2 years?



How many have an EHCP?



Written evidence from the Parents of children with M.E. / CFS Support Group  
'Parliamentary call for evidence 2018'

MEDICALNEEDSINSCHOOLS.CO.UK

---

# THANK YOU

## ***Contact us:***

MNIS email

[mnis@ohs.oxon.sch.uk](mailto:mnis@ohs.oxon.sch.uk)

My email

[steve.lowe@ohs.oxon.sch.uk](mailto:steve.lowe@ohs.oxon.sch.uk)

MNIS website

<https://medicalneedsinschools.co.uk/>

OHS website

<https://ohs.oxon.sch.uk/>

---



@MNIS\_Oxon

# Resources

- [Long Covid Kids](#) Schools
- [Long COVID Physio](#) Resources —adult-based but some useful video clips for explaining long covid and some of the associated difficulties
- [Royal College of Occupational Therapists \(RCOT\)](#) A quick guide for OT's: Occupational Therapy and children and young people with Long Covid (Post COVID-19 syndrome)
- [Your COVID Recovery](#) Children and young people with COVID -
- The Long Covid self-help guide – practical ways to manage symptoms
- The Long Covid Handbook – world leading expert advice on understanding, managing and treating long covid
- NICE guideline - managing the long - term effects of Covid 19
- Young Minds- [youngminds.org.uk](http://youngminds.org.uk)
- HealthTalk: Family experiences of long COVID

A video of this presentation will be on the Medical Needs in Schools website in the next few weeks

---

# FEEDBACK

---

Link in the chat



# Q & A

---

Moderator: Dr Emma Dunford

# FEEDBACK

---

Link in the chat

# THANK YOU

---

[CYPlongcovid.Service@ouh.nhs.uk](mailto:CYPlongcovid.Service@ouh.nhs.uk)