

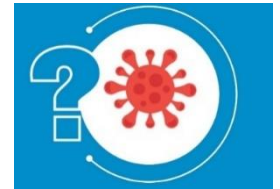
Alder Hey Long Covid Team

Long Covid

A resource for young people and their parents

What is Covid-19, or Coronavirus?

The current coronavirus outbreak, or COVID-19 as it's officially known, was first detected in China in December 2019. Coronavirus has been in the news a lot because there have been cases in lots of different places around the world, including here in the UK, which can make it seem quite scary.



Coronavirus is a group of infectious diseases that range from a common cold to a more serious illness which affects your lungs and breathing. When people are unwell with Covid 19, they may have symptoms such as a cough, a fever, and/or difficulty breathing.

You can find out how Alder Hey are managing covid19 on the link below:

<https://covid19.alderhey.nhs.uk/faqs/>

What is Long Covid?

The COVID-19 pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has rapidly spread worldwide. Globally, children and adolescents make up a small proportion of acute severe COVID-19 cases and for the majority the acute illness is mild. There are reports internationally of small numbers of children and adolescents developing a delayed onset illness, Paediatric Inflammatory Multisystem Syndrome, temporally associated with SAR-CoV-2 (PIMS-TS) and also reports that children may be affected by prolonged ill-health as a consequence of Covid-19, known as 'Long Covid'. This new and emerging condition can have a significant effect on quality of life and be associated with organ damage or impairment.

There is a minimal, although evolving, evidence-base in Long Covid. It is important to recognise that people who had mild acute Covid-19 can develop Long Covid. The most common symptom reported is fatigue, but symptoms across multiple systems are reported and, in some adults, there is evidence of organ damage. There are reports of children having similar prolonged symptom clusters to adults, following suspected or confirmed Covid-19 infection, but further research is needed to establish whether children may also suffer organ impairment. Peri-myocarditis has been reported in one small case series of children with Long Covid symptoms.

It is important that an early, thorough, holistic medical assessment is performed in children with possible Long Covid, to ensure appropriate identification of those with organ impairment requiring further specialist input and management, as well as recognising and offering appropriate support for symptoms which can cause significant morbidity and reduced quality of life.

Definition

NICE (National Institute for Clinical Excellence) produced **Covid-19 rapid guideline: managing the long-term effects of Covid-19** for adults and children. This introduced the following clinical definitions for the initial illness and Long Covid at different times:

- **Acute COVID-19:** signs and symptoms of COVID-19 for up to 4 weeks.
- **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from 4 to 12 weeks
- **Post-COVID-19 syndrome:** signs and symptoms which 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.
- **Long COVID:** 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).

It is not necessary for the patient to have had a positive test for COVID when they were acutely ill to meet this definition.

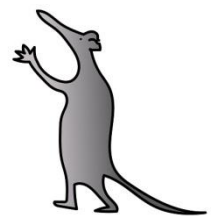
The Office for National Statistics (April 21) suggests that around 7.4% of children aged 2 to 11 years and 8.2% of children aged 12-16 years had persistent symptoms at 12 weeks. Data for longer intervals is not yet available. Another study, using the Zoe Symptom Tracker App, reported 13% of those who had COVID-19 had persisting symptoms at 28 days.

How might I feel if I have Long Covid?

Everyone is different, and lots of people might have different symptoms, or have different symptoms at different times. We know that it is not unusual to feel, or to experience, any of the below....

Symptoms:

- Respiratory symptoms: breathlessness, cough
- Cardiovascular symptoms: chest tightness, chest pain, palpitations
- Generalised symptoms: Fatigue, fever, Pain, hair loss
- Skin rash
- Neurological symptoms: cognitive impairment (brain fog), sleep disturbances, peripheral neuropathy
- Gastrointestinal symptoms: abdominal pain, nausea, diarrhoea
- ENT symptoms: Tinnitus, earache, sore throat, loss of taste/altered taste, loss or altered smell
- Autonomic symptoms: dizziness, vertigo
- Musculoskeletal symptoms: non-specific joint pains, muscle pain
- Psychological symptoms: mood changes, anxiety, low mood



Differential diagnoses:

The spectrum of symptoms for children and adults with Long Covid is broad and therefore the differential diagnosis for children presenting with the features of Long Covid is wide-ranging. It is important to consider a differential diagnosis and investigate appropriately for other causes for the presenting symptoms.

Dependent on symptom presentation the differential might include:

- Rheumatological conditions e.g. JIA, SLE, Dermatomyositis
- Inflammatory conditions e.g. IBD
- Chronic infections, including reactivation (eg TB, HSV, EBV)
- Malignancy – for example leukaemia, lymphoma
- Autoimmune – Coeliac disease, Thyroid disorders
- Adrenal insufficiency
- Organ impairment – renal, liver, pancreatic, cardiac, respiratory
- Neurological conditions – Venous sinus thrombosis, malignancy, stroke, neuromuscular conditions
- Mental health difficulties including low mood, chronic fatigue

Managing Long Covid

We know that having long covid can be difficult. By reading the information in this resource, we hope that this may help you to find ways of being able to better manage living your life, whilst long covid is around.

We will share ideas which involve managing your daily activity levels. We will talk about ways to strengthen your body and improve your stamina. We will talk about sleep, as well as exploring some of the ways which you might be feeling emotionally at this time.



What is Pacing?

Pacing is about balancing activities throughout the day to help to manage symptoms of pain and fatigue, which can often be experienced because of Long Covid. It's about finding a level of daily activity which can be managed and achieved, no matter how you are feeling that day.

Everyone is different and their activity levels will also be different. This can vary depending on a number of things, including what is going on in your life and how you feel both physically and emotionally.

When people experience pain or tiredness, a natural reaction is for their level of activity to drop. It is the body's way of protecting itself.

When activity levels stay low for a while, fitness and motivation to do things decreases and our mood can also be affected. This can lead to reduced confidence and can change how you feel about yourself. You might start to find you are missing out on things you used to do, and we understand that this can feel tough.

Young people often describe that they have good and bad days. On a good day, they might try to 'catch up', and try to return to a previous activity level. They might find that due to reduced fitness and weaker muscles, that this brings an increase in pain and/or tiredness and are then unable to keep up with these activity levels.

People may describe that they 'pay for it' over the next few days, when everything feels worse, and they can even have lower activity levels than before. We call this cycle "boom and bust", with a rollercoaster pattern of over and under activity.

Pacing is the opposite to boom and bust, and means starting off lower, and gradually building up activity levels over time, in small gradual steps. Spreading your activities and energy levels across the day or week. When you start pacing, you may experience an increase in symptoms, and you may feel your activity levels may drop. However, by continuing to pace you are unlikely to drop to previous low levels and should be able to do more by spreading your activities out. Applying the skills you have learned will help you bounce back quicker!

What is Boom and Bust?

The boom and bust cycle below help to illustrate how pacing is important to maintain consistent energy levels.

The 'boom and bust' cycle occurs when we feel we have more energy than at other times in the day (boom) and as a result we can use up all our energy, leading to exhaustion and long periods of 'recharge' (bust).

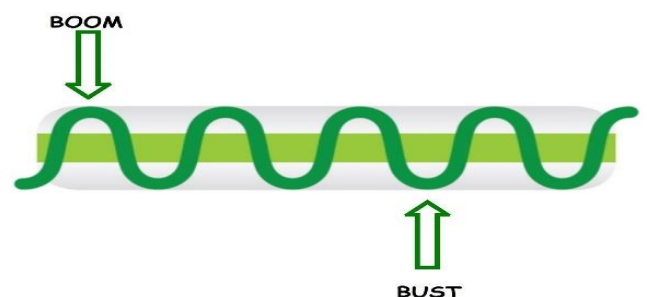
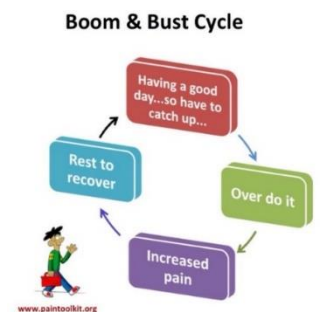
When our energy levels are higher, we want to do as much as possible. However, this can lead to periods of fatigue and enforced rest, overall reducing the amount of activities we can take part in.

The boom and bust cycle are managed by strategies such as pacing.

We understand that pacing may not seem very appealing at first; it may feel that you can't do what you want to do when you want to do it. It might be annoying or frustrating, or make you feel sad.

Maybe you're having a good day, and you feel tempted to do lots more...we aim to help you to appreciate that there might be some disadvantages to this.

The more you use pacing, the more beneficial it can become. Avoiding that rollercoaster of over and under activity, to give you back control, having strategies to manage the impact of long covid.



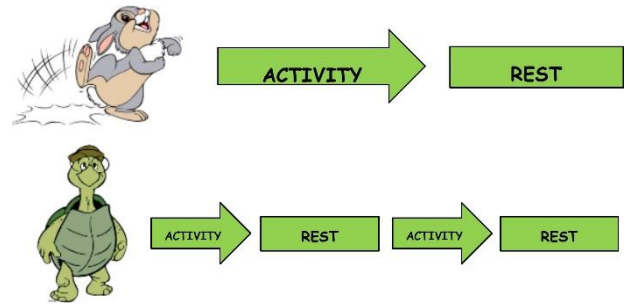
How do I pace?

The same way you climb a mountain.....one step at a time :)

- **Prioritise** and spread out activities over the week/day. Think about things you must do and things you want to do over the week. We need to get a balance between school, home life and leisure/social.
- **Break down** activities into smaller steps where you can
- **Set baselines** – what level of activity can you manage every day without causing an increase in symptoms? Can you do this consistently?
- **Consistency** means doing the same levels of activity every day – this doesn't have to always be the same activity
- **Plan**, this will help you avoid over and under activity.... consider what is coming up later in the day or week. What strategies can you plan to use to manage an activity?
- **Balance** different activities and think about what is involved in the activity, the physical, cognitive and social aspects
- **Breaks & Rest**, it's important to change what you might be doing after a while. This doesn't always have to mean stopping and sitting...a restful activity might include reading, tv, a walk, being by yourself, a bath, creative activities, music, mindfulness
- **Progression** - gradually increase your activity level in a graded way
- **Managing challenges** – using relaxation, breathing techniques and body scan techniques to help manage any tricky thoughts and feelings which might show up
- **Goal setting**...knowing what you want to work towards achieving will help you to keep going with your pacing



The hare and the tortoise; Over time, the more we pace ourselves during activity, the more beneficial it will become. By avoiding periods of over and under activity like the tortoise, we are in control of our energy levels by using useful strategies to manage symptoms. If pacing isn't used, as shown by the hare, exhaustion and prolonged rest periods may occur which can prevent us from participating in activities and tasks we want and need to do.



Getting active again...

The benefits of exercise;

- Keeps you supple
- Endorphin release
- Increase energy levels
- Helps with sleep
- Improves strength and stamina



Exercise helps to keep you moving, it keeps you supple, and it keeps your joints as they should be, preventing them from becoming out of condition.

Exercise releases endorphins, your happy hormone, and can therefore make a difference to your moods and feelings.

Exercise increases your energy levels – this may sound a little strange at first when you're tired and in pain, but after doing some physical activity, as long as you do this in a paced and graded way, exercise can give you more energy.

Exercise can also help with sleep. It can help to regulate your body's day and night patterns, improving the quality of sleep at night due to how you've been making energy during the day.

Fatigue

What is fatigue?

Fatigue is very common in long covid, for children and young people as well as adults. Fatigue can be hard to manage and can cause us to feel tired and exhausted all or most of the time. Our muscles can start to feel weak when we become fatigued, meaning we struggle to do all the things we want to on a daily basis. Our reaction times can become slower, meaning we might find it difficult to play games or take part in PE.



The more fatigued we become, our brains can become fuzzy and we might find it difficult to concentrate. This may affect us in school and when doing work as we aren't able to work as quickly. Fatigue can also affect our ability to care for ourselves and can contribute to losing interest in our hobbies, favourite activities, and our friends. This can lead us to feel even more tired.

Sleep

Due to how you have been feeling, you might have noticed that your sleep has been affected, and you might not feel as refreshed in a morning as you used to do. This is normal in children and young people experiencing long covid.



What can I do to help to improve my sleep?

- Stay active using a pacing approach
 - ✓ Eat well
 - ✓ Stick to regular routines
 - ✓ Remember that bedrooms are for sleeping, try avoiding overusing your bedroom in the day/early evening
 - ✓ Create a comfortable space, low lighting, not too much clutter
 - ✓ Breathing techniques can help to calm the mind
 - ✓ Progressive Muscle Relaxation can help to let go of tension
 - ✓ Imaging a safe or calming place, can help you drift off as you relax
 - ✓ Meditation / Mindfulness can help to bring your mind back to the present moment

Breathing Techniques

Breathing techniques can help at any time of day, as well as to help prepare the body for sleep. They can help;

- Calm the nervous system
- Quieten the mind



It can be useful to practice these during the day, and also when you are winding down for bed. There are many different techniques such as:

1. Box breathing/Square breathing

<https://www.youtube.com/watch?v=tEmt1Znux58>



2. Circle breathing;

<https://www.youtube.com/watch?v=aNXKjGFUIMs>

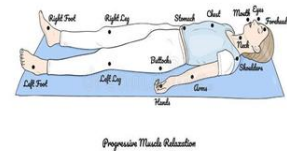
3. Three-minute belly breathing;

https://www.youtube.com/watch?v=sn_2GY1gTy0



Progressive Muscle Relaxation

- Muscle tension is a common response to physical or emotional difficulties
- Tense muscles feel more pain and can become more tired
- Progressive Muscle Relaxation, can help relieve stress, anxiety and symptoms of pain
- This involves a technique of squeezing muscles and then relaxing



<https://www.youtube.com/watch?v=JPrKsWgl66g>

Imagery



There are different ways to engage in imagery, and did you know that this is also a relaxation technique?! We'd like to tell you about ways you can use your imagination to help bring about a sense of stillness, and of calm.

Imagery works best when you use all of your senses, to create a picture in your mind's eye - imagining in your chosen place, what you can see, hear, touch, smell and even taste.

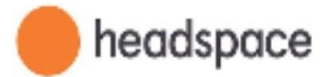
- Start by getting comfortable in a quiet place where you won't be disturbed, and take a couple of moments to focus on your breathing, close your eyes if you wish, and just notice what's going on in your body....become aware of any tension in your body, and let that tension float away each time you breath out.
- Imagine a place where you feel calm, peaceful and safe. It may be a place you've been to before, somewhere you've dreamed about going to, somewhere you've seen a picture of, or just a peaceful place you can create in your mind's eye.
- Look around you in that place, notice the colours and shapes. What else do you see, what else do you notice?
- Now notice the sounds that are around you, or perhaps notice the silence. Notice any sounds far away, notice any nearer to you.
- Think about any smells you notice...maybe you smell grass, the sea, anything at all where you are.
- Now focus on anything you can feel, that you imagine touching....maybe the earth beneath you, the chair you imagine sitting on, how does the temperature feel, can you feel a breeze?
- Notice the pleasant, physical sensations in your body, whilst you enjoy just being here, in this safe place.
- Now whilst you're in your peaceful and safe place, you might choose to give it a name, whether one word or a phrase that you can use to bring that image back, anytime you need to.
- You can choose to linger there a while, just enjoying the peacefulness and calmness. You can leave whenever you want to, just by opening your eyes and being aware of where you are now and bringing yourself back to alertness in the 'here and now'.
- Remember, this is a special place, a place that lives within you, a place you can visit any time you choose.



Mindfulness

Mindfulness is a way of training our awareness to come back to the present moment, when maybe it has wandered off to the past, or wandered away to the future. This is not done by trying to turn off thoughts and feelings, or get rid of them, but instead by learning to observe them without judgement, much like you might notice cars passing on the street, or clouds moving through the sky. Focusing on your breath and using your senses to tune into the present moment.

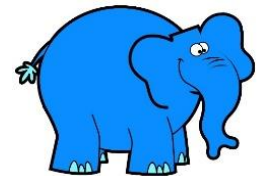
You could think of it like anchoring yourself, holding yourself steady whilst tricky thoughts and feelings pass by. There are several apps and websites which have helpful exercises you could try, including:



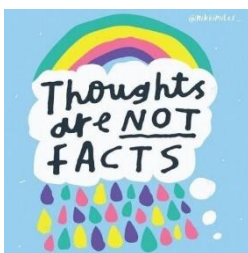
A video about the idea of training the mind;
<https://www.youtube.com/watch?v=iN6g2mr0p3Q>

Managing tricky thoughts and feelings

Thoughts and feelings can at times be tricky to have around. They can show up when you don't want them to, and sometimes they stick around, no matter what you do. Have you ever tried hard to stop thinking about something? To just get rid of it from your mind? Maybe try this.... don't think about a blue elephant.... whatever you do don't think about it.... how did you get on? It's not easy is it! I wonder as you carry on reading this resource, how many times a blue elephant will pop into your mind? Chances are, you'll think about it more, now that you're trying not to.



Thoughts are very powerful, and they can have an impact on the way we feel and the things we do. We have thousands of thoughts each day. Most come and go before we even notice, but others can stick around in our minds for a long time.



If you use all your energy trying to push away and ignore difficult thoughts and feelings, you might find that you have less time, or find it harder, to focus on what really matters to you. It's ok to not want worry, or sadness to be around. To not want to be thinking some of those unhelpful thoughts that keep popping into your mind. However, by acknowledging that they are there, and dropping the struggle you might be having with them, you might find they lose some of their power.

It is normal for us all to experience difficult thoughts, as well as tricky feelings. This is just how we have evolved. If you feel that you sometimes get stuck in a cycle of struggling with difficulties...try to pause for a moment...notice what is going on for you...and try to remember..... thoughts are not facts.

Just because you have thought, it doesn't mean that it is true. Our minds can be great story tellers, but whilst your mind thinks it's helping you out by thinking and over thinking, remember, not everything that your mind says, is necessarily true.

A video about how we have inherited a caveman mind;
<https://www.youtube.com/watch?v=kv6HkipQcfA>



A video about how you are not your thoughts;
<https://www.youtube.com/watch?v=0QXmmP4psbA>

Thoughts, Feelings & Behaviour

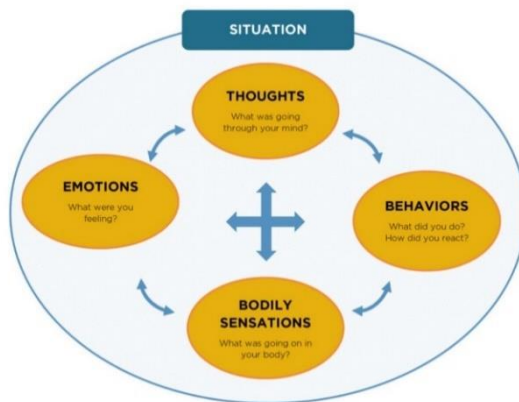
As we've read, all day long thoughts run through our minds, coming and going. Every time we face a situation, our mind has a thought about it....I wonder what thoughts have gone through your mind whilst you've been reading this resource?

Maybe thoughts such as...

- Pacing makes sense, I'll try that
- This is interesting
- I'm glad I read this
- This doesn't apply to me
- Nothing's going to work
- I hate long covid
- Where's my phone gone?
- What's for tea?
- Ooh that new films on tonight....



Thoughts can be linked to the situation we are in, thoughts can be in the form of judgements, thoughts can be critical or supportive, and at times they can be just random!



The diagram above, shows that how we think, how we feel, how we behave, and what goes on inside our bodies, are all connected.

It's how we make sense of the way that people can be in the same situation as each other but can have very different responses. Imagine putting a group of people into a theme park.... some people will be excited going on rides, some people will be scared, some people will be bored, some people might even get angry. Why? The way people perceive a situation, what they think of it, what it means to them, can have an impact on how they behave, what happens to their moods and feelings, and how their bodies react. I wonder which feelings you might have experienced? The next time you notice a feeling showing up, pause for a moment, and notice what thoughts might be around.



Ask yourself...is there another way of looking at this situation?

What might a friend, or family member say, if they knew what I was thinking?

See how your hot cross bun looks and see what happens if you can challenge any thoughts which are around.

Remember that our behaviour also impacts how we think and feel. Take notice of your behaviours when certain feelings show up and ask yourself if there are any other ways of responding right now.

‘Brain Fog’

Sometimes children and young people who have long covid can experience ‘brain fog’. This just means that sometimes you might feel a bit more forgetful, you might struggle to concentrate, or just feel that things are a bit muddled up. If you have any difficulties with remembering information, concentrating or making sense of things, here are some strategies you might find helpful;

- Rehearse and repeat information you hear
- Chunking; break information down into smaller chunks
- Write it down; post it notes can be really helpful
- Use rhyming to remember things
- Take breaks
- Ask for help
- Sometimes having a short ‘time out’ from class can help
- Remember your breathing and mindfulness techniques



We hope that you have found reading this resource helpful. We appreciate that there isn't a 'quick fix' to long covid, however we hope to reassure you that by trying out the advice and strategies here, that this may support you to get back to living the kind of life which matters to you.

With best wishes,

The Alder Hey Long Covid team

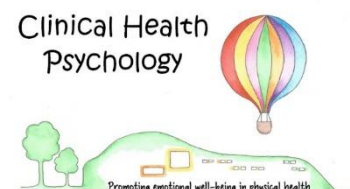
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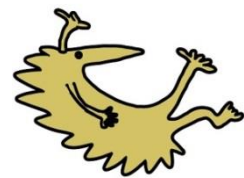
This leaflet only gives general information. You must always discuss your individual treatment with the appropriate member of staff. Do not rely on this leaflet alone for information about your treatment.

This information can be made available in other languages and formats if requested.

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