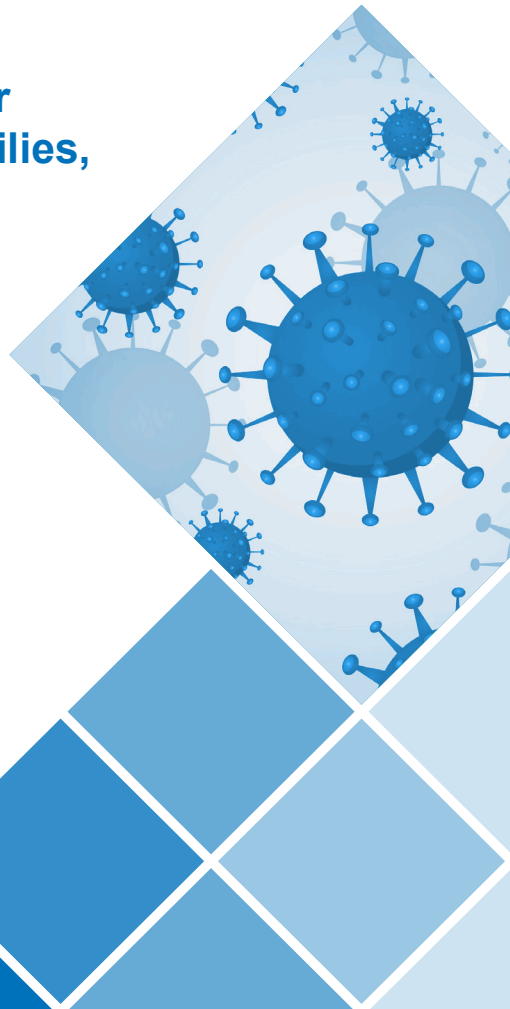




**Mersey Care**  
NHS Foundation Trust

# Liverpool Long COVID Team

**Fatigue management for  
young people, their families,  
and carers**



## Managing Long COVID

We know that having Long COVID can be hard. By reading this information, we hope you may find ways of being able to better manage living your life whilst experiencing Long COVID. We'll share ideas such as: managing your daily activity levels, strengthening your body, improving your stamina, sleep and exploring some of the ways which you might be feeling emotionally too.



### Fatigue - what is it?

Fatigue is an extreme tiredness and is very common in Long COVID, for children and young people as well as adults. Our muscles can start to feel weak when we become fatigued, meaning we struggle to do all the things we want to do. 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.

Fatigue can also affect our ability to care for ourselves and can contribute to losing interest in our hobbies, favourite activities and socialising. This can lead us to feel even more tired.

## Sleep

Due to how you've been feeling, you might have noticed that your sleep has been affected, and you might not feel as refreshed in the morning as you used to. Some tips to combat this include:

- Sticking to the same bed time and wake up time
- Avoid using your bedroom for other things than sleep
- Removing distractions, lights and sounds
- Ensuring your bedroom is the right temperature and you can block out outside light.
- Winding down, maybe have a bath or a warm drink
- Avoid gaming or watching TV just before bedtime
- Make sure your bed and pillow is comfy



## 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're feeling that day.

When people experience pain or tiredness, a natural reaction is for their level of activity to drop. 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.

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.

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.

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

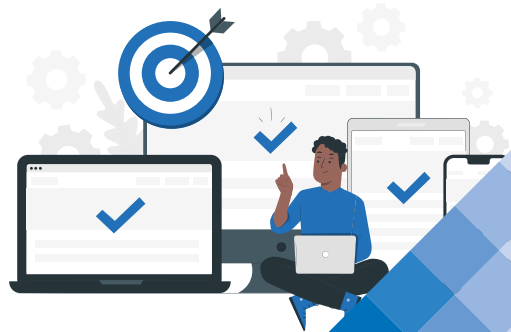
We understand that pacing may not seem very appealing at first. It may feel that you can't do what you want to do when you want to do it. It might be annoying or frustrating, or make you feel sad. Maybe, you're having a good day, and you feel tempted to do lots more, we aim to help you to appreciate 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 activities over the day or week. Think about things you must do and things you want to do. We need to get a balance between school, home life and leisure
  - **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 manage an activity?
  - **Breaks and 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 when you no longer have crashes of fatigue.
  - **Managing challenges**, using relaxation, breathing 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.
- Rest before needing a rest!**



## Breathing techniques

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



Box breathing/  
square breathing



Circle breathing



Three minute belly  
breathing

## Progressive muscle relaxation

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



Scan the QR code for a  
helpful guidance video



## Mindfulness

Mindfulness is a way of training our awareness to be present 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. This is done by 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:



## Managing tricky thoughts and feelings

It's 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 and notice what's going on for you. Try to remember that thoughts are not facts.

Just because you have thought, it doesn't mean that it's true. Our minds can be great story tellers.



A video about how we have inherited a caveman mind



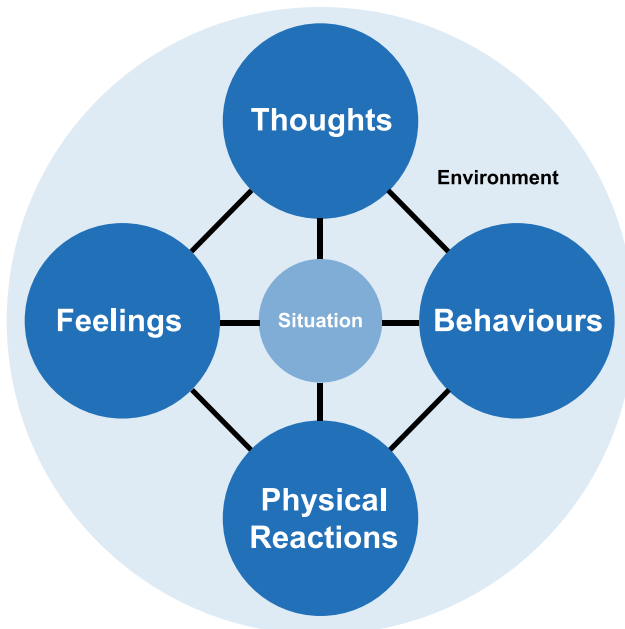
A video about how you are not your thoughts

## Thoughts, feelings and behaviour

All day long thoughts run through our minds, coming, and going. Every time we face a situation, our mind has a thought about it. Some thoughts that you may have thought could be:

- 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

Thoughts can be linked to the situation we're 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 on the previous page 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 think of a situation can have an impact on how they behave, what happens to their moods and feelings, and how their bodies react.

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?

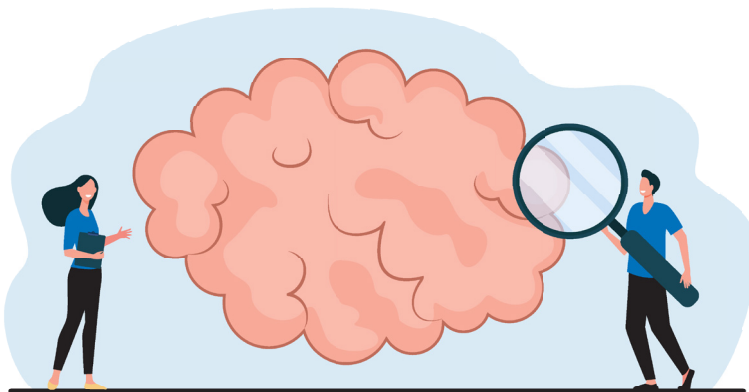
Remember that our behaviour also impacts how we think and feel. Take notice of your behaviours when certain feelings show up and ask yourself if there are any other ways of responding right now.

## 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
- Break information down into smaller chunks
- Write it down, post it notes can be helpful
- Use rhyming to remember things
- Take breaks, sometimes a 'time out' in school can work
- Ask for help.

Remember your breathing and mindfulness techniques.



We hope that you've found reading this information helpful. We appreciate that there isn't a 'quick fix' to Long COVID, however, we hope to assure you that by trying the advice and strategies here, this may support you to get back to living the kind of life which matters to you.

## Liverpool Long COVID Team

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If you have any comments, compliments or concerns you can speak with a member of staff or contact our Patient Advice and Liaison Service (PALS) and Complaints Team.

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Adapted from original information provided by  
Alder Hey Children's NHS Foundation Trust.