

## **Brain Health Breakthrough CIC - Long Covid Resource**

**Updated: April 2024**



According to NICE guidelines (last updated January 2024), there are 3 different types of illness related to COVID-19;

- 1) Acute COVID-19 - with symptoms lasting up to 4 weeks
- 2) Ongoing symptomatic COVID-19 - with symptoms lasting up to 12 weeks
- 3) Post-COVID-19 syndrome - with symptoms continuing past 12 weeks, with no alternative diagnosis available.

Long Covid usually presents with a variety of symptoms, which often overlap and fluctuate in severity. The term 'Long Covid' is used to describe both ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

**Long Covid has over 200 listed symptoms, the most common symptoms include:**

- **Extreme exhaustion/fatigue**
- **Problems with memory/concentration**
- **Shortness of breath/chest pain**
- **Heart palpitation/chest tightness**
- **Muscle/joint pain**
- **Insomnia**
- **Mood changes.**

### **Long Covid: Hidden Disability**

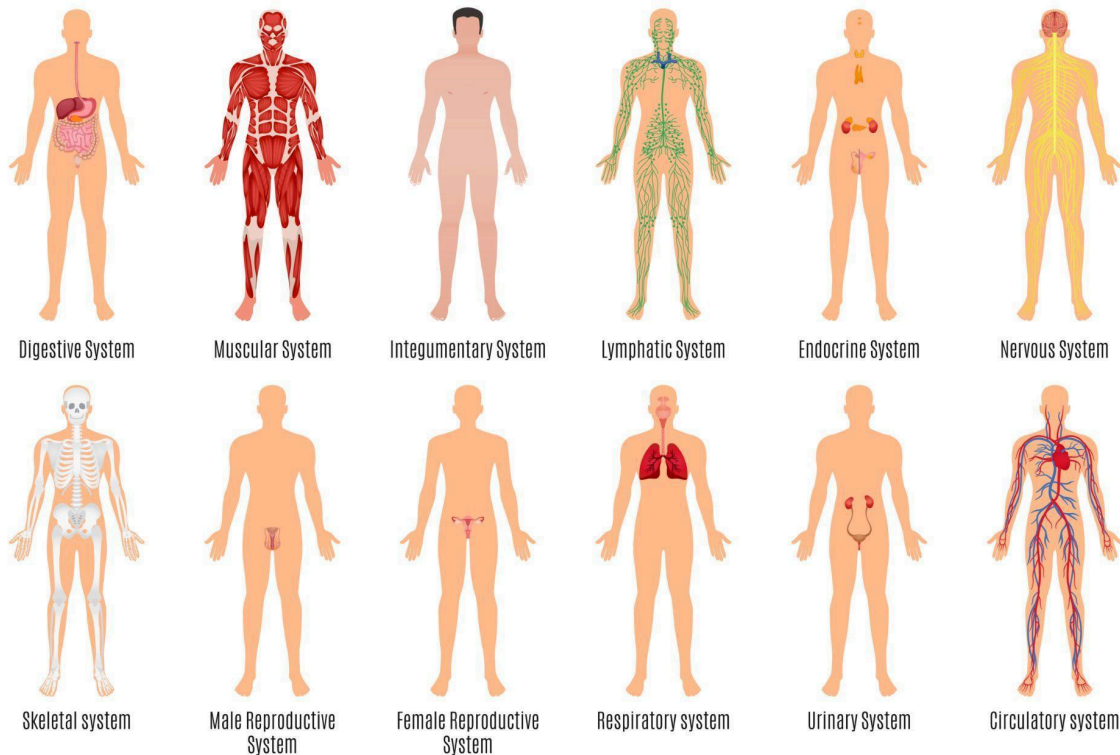
You may feel like friends and family don't understand your experience, as you look normal, but inside you may be struggling with simple everyday tasks.

**This is known as a hidden disability/invisible illness.**

You also may have had medical tests (such as blood tests, chest x-rays, etc.), which come back with normal results, yet you feel something is wrong and you aren't your normal self.

**For further information go to the section of the website: employers, family, and friends.**

## HUMAN BODY ORGAN SYSTEMS



**For further resources go to the section on the website: Audio resources Long Covid playlist and click the link to 'Audios'.**

### **How are you affected?**

**The virus can affect any part of your body and can relate to one or more of your body systems.**

We have 11 body systems that help us stay healthy and regulate our bodies (see diagram). This explains the varied and changing symptoms, which can feel worrying and distressing to experience. It helps to realise that your whole body is impacted by the effects of being infected by coronavirus and you aren't alone. If you are worried, we would always recommend visiting your GP and have your symptoms checked out.

Brain Health Breakthrough also runs peer support groups. For more information, visit: <https://brainhealthbreakthrough.co.uk/long-covid-peer-group-1>

## What is Extreme Fatigue (Chronic Fatigue Syndrome)?

After a good night's sleep do you wake up still feeling tired?

Is it a challenge to do daily activities, for example washing, dressing, cooking?

Do you feel too exhausted to get out of bed at all?

### **You might be experiencing fatigue.**

With Long-Covid, you may experience extreme fatigue. This may leave you wondering why you feel exhausted. You may have to cut down on activities that you used to do before catching COVID-19. Every task you do adds to the depletion of the amount of energy you have. Sometimes we can forget to acknowledge that daily activities still use up energy, these are some examples:

- Using your cognitive function
- Screen time
- Sensory overload
- Daily routines
- Walking
- Socialising with friends, family, or at work.

## Understanding “Crashes”

**Fatigue and post-exertional symptom exacerbation** World PT Day 2021

**FATIGUE**  
Fatigue is a feeling of extreme exhaustion and is the most common symptom of Long COVID. It:  
• is not easily relieved by rest or sleep  
• is not the result of unusually difficult activity  
• can limit functioning in day-to-day activities  
• negatively impacts quality of life

**PESE**  
Post-exertional symptom exacerbation (PESE) is a disabling and often delayed exhaustion disproportionate to the effort made. It is sometimes described as a "crash". The activity that can trigger this worsening of symptoms can be something that was easily tolerated before, such as:  
• a daily activity (eg a shower)  
• a social activity  
• walking (or other exercise)  
• reading, writing or working at a desk  
• an emotionally charged conversation  
• being in a sensory environment (eg loud music or flashing lights)

Many of the symptoms experienced by those living with Long COVID are very similar to those of myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).  
The World Health Organization recommends that Long COVID rehabilitation should include educating people about resuming everyday activities conservatively, at an appropriate pace that is safe and manageable for energy levels within the limits of current symptoms, and exertion should not be pushed to the point of fatigue or symptom exacerbation.

PESE is most often triggered by physical activity and exercise. Nearly 75% of people living with Long COVID still experience PESE after 6 months. The symptoms worsened by exertion can include:  
• disabling fatigue/exhaustion  
• cognitive dysfunction or "brain fog"  
• pain  
• breathlessness  
• heart palpitations  
• fever  
• sleep disturbance  
• exercise intolerance

Symptoms typically worsen 12 to 48 hours after activity and can last for days, weeks or even months.

Your physiotherapist can guide you in pacing as an activity management tool that is also used successfully for people with ME/CFS to prevent triggering PESE.

**STOP** trying to push your limits. Overexertion may harm your recovery.

**REST** is your most important management strategy. Do not wait until you feel symptoms to rest.

**PACE** your daily activities and cognitive activities. This is a safe approach to navigate triggers to symptoms.

Physical activity and exercise interventions warrant caution as rehabilitation strategies among people with Long COVID and persistent symptoms of disproportionate breathlessness on exertion, inappropriate high heart rate (tachycardia), and/or chest pain. Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.

World Physiotherapy  
[www.world.physio/wptday](http://www.world.physio/wptday)

**Post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE) is a disabling and often delayed 'crash' which is disproportionate to the effort made.**

**You can download the 'Fatigue and post-exertional symptom' poster in the download section on the website.**

Activities that trigger it may be simple daily activities that were well-tolerated before Long-COVID eg. a shower, walking, socialising. Post-exertional symptom exacerbation is different to normal tiredness after exercise. It is more debilitating and

takes more rest to recover back to your baseline. Normally, increasing activity gradually increases fitness. PESE gets worse with increasing activity, however, it can be managed with pacing.

## **Pacing**

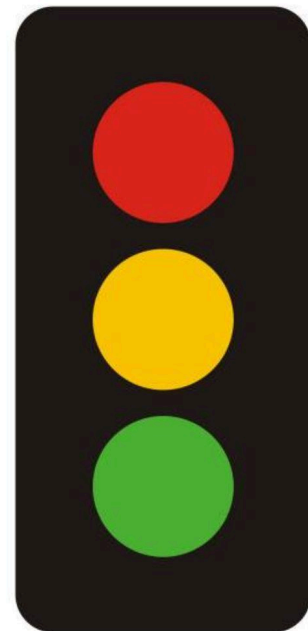
### **STOP. REST. PACE.**

Overexertion may harm your recovery. Rest is most important, and it is vital that you don't wait for symptoms to arise before you make time to rest. Pacing is a safe approach that can be used to navigate triggers that lead to increased symptoms.

Stop what you are doing before extreme fatigue is triggered

Rest, relaxation, breathing or lie in bed

Return to activity using pacing: take breaks, move at a slower pace, break tasks up over a longer time frame



## **Spoons Theory**

“The Spoon Theory is a creative way to explain to health friends and family what it’s like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons for the next day.

### **If you only had 12 spoons per day, how would you use them?**

Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal.

Take away 4 spoons if you have a cold.”

(Taken from 'The Spoon Theory' written by Christine Miserando)


**You can download the 'Spoons Theory PDF' in the 'downloads' section of the website.**

**The Spoon Theory**

DYSAUTONOMIA INTERNATIONAL  
AWARENESS ADVOCACY ADVANCEMENT

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

**If you only had 12 spoons per day, how would you use them?** Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

 get out of bed	 bathe	 make & eat a meal	 go to work/school
 get dressed	 style hair	 make plans & socialize	 go shopping
 take pills	 surf the internet	 light housework	 go to the doctor
 watch TV	 read/study	 drive somewhere	 exercise

The Spoon Theory was written by Christine Miserando, which you can check out on her website [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com).

[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)

**Prepare what you need for activities ahead of time by using the three Ps. This helps with general cognition and to reduce brain fog.**



### Lifestyle Adjustments

- Understanding the impact of living with Long-Covid has on your body can help you to implement adjustments to your lifestyle which support your recovery.
- Using techniques, such as Pacing and The Spoons Theory, can help you (and others) understand and manage your new level of energy.
- It is important that you plan, prioritise, and pace to manage your routines to reduce fatigue and prevent crashes.
- Trying to accept that you will have good days and bad days, and that your life has changed since you contracted COVID-19.

### Your Rights

If you have had Long-Covid for over 12 months, and it affects your daily living, you have a disability according to the definition in “The Equality”.

Whilst supporting people with Long-Covid, we have seen some confusion on what legal protections individuals are entitled to. This includes what an employer’s duties are towards them, and whether people with Long-Covid are protected under the Equality Act 2010.

*“You’re disabled under the Equality Act 2010 if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do*

*normal daily activities."*

– Disability Equality Act 2010

### **What can you do to help yourself?**

By acknowledging that Long-Covid is a challenge within your daily life and that it is impacting your body systems and capacity for daily activities, you can positively impact your own recovery.

Below are some tips to help you with your recovery journey and additional links to resources you might find useful.

- 1) Acceptance - by accepting who you are now is a process, but acknowledging that acceptance has different levels can help. The more we can embrace who we are will help us to be more present in our lives and better navigate our daily lives. By living in the past, we can hinder our recovery progress. The more you focus on now and the future, the better your recovery will be.
- 2) Rest & Relaxation - understand that simple tasks can still stimulate our minds and this overstimulation can lead to increased risk of fatigue. Some suggestions for resting include; breathing techniques such as one hand on your stomach and focus on the breathing movements or listening to calming music on YouTube to soothe the nervous system, listen to podcasts/audios to help you retrain your thinking - you can learn more about using positive language here.
- 3) Readjusting your hobbies - having Long-Covid means that previous hobbies may no longer be helping your wellbeing. It is important to seek out adjustments or replacements for things that bring you joy, without causing fatigue. Examples include; crafting with regular breaks and not focusing on the outcome, sitting outside in the garden or taking shorter walks to be out in nature - you can even use visualisation around being out in nature hiring scooters in a group to get out into nature, and seated yoga and exercise options
- 4) Self-care and compassion - being kind and compassionate with yourself will help your overall recovery journey progress. This can be part of the acceptance process. Some things to consider; treat yourself like you would others, implement mindset changes and inner voice alterations, increase self-care and wellness activities, and use the resources on this page..
- 5) Mindset changes - experiencing Long-Covid symptoms can impact your daily life and your self image. You can change the way you think about your new life by resetting your neuro-pathways with the repetition of positive messages. More information in the wellness toolkit.

**For more information see the 'Wellness Toolkit' section of the website.**

**Useful links:**

<https://www.yourcovidrecovery.nhs.uk/>

<https://www.yourcovidrecovery.nhs.uk/i-think-i-have-long-covid/>

<https://www.mind.org.uk/>

Unpaid Carers

<https://www.n-compass.org.uk/>

<https://www.carerslinklancashire.co.uk/lancashire-carers-service>

<https://www.bwdcarers.org.uk/>