

# Long COVID Information Pack

## Contents

Public Event slides.....	3
Long COVID Public Event: Questions .....	29
Resources.....	35
Energy Conservation .....	36
Fatigue and post-exertional symptom exacerbation.....	39
Activity Diary .....	40

Public Event slides

# LIVING WITH LONG COVID

## Support in Birmingham and Solihull

### Join the conversation



## Who are we?

## Who is leading this conversation?

- We are health professionals from across different Birmingham and Solihull health organisations
- We worked together to create a service for supporting patients with Post COVID Syndrome, commonly called Long COVID
- We want to share more information with local people like you to support you to manage your condition and access support when you need it

### Introducing members of the panel

# House keeping

## Help us make this conversation work!

### Keep your mic muted

Most important. Please keep your mic muted unless you are invited to speak.

### Avoid talking over others

Unlike an in-person meeting, its sometimes difficult to distinguish between multiple conversations leading to confusion

### Camera use

Being able to see each other enables a more personal interaction. In larger meetings, when slides are being shared you will only be able to see the person who is talking. Be sure to turn off your camera if it might be distracting to others e.g. if walking with your camera on (mobile device)

### The chat box

If you ask questions in the chat window, please be conscious that anyone invited, has access to view all of the chat

### Questions

Please use the chat function if possible. Alternatively raise your hand using the raise hand function to ask a question.

If you don't have the opportunity to ask a question, during the event, or you question isn't answered – don't worry. We will send more information after the event.

# About Long COVID

## Dr Nandan Gautam

# What is 'Long COVID'

## What are the main symptoms and issues?

- Breathlessness
- Fatigue
- Myalgia
- Poor concentration: brain fog
- Anxiety (consequences of critical care)
- Smell: paraosmia
- Taste: ageusia
- Hair, nails, skin, gi tract, menstrual cycle, sex

## How are people recovering

- Around 40% get better within 12 weeks
- 90% get better within 9 months

Of the remaining patients:

- 15% unmask new disease
- 20% manage symptoms

What is the picture like in Birmingham and Solihull? How about the rest of the UK?

# What is 'Long COVID'

## More about the condition

- Why do some people get long symptoms?
- What is the immune response?
- What can we do about it? Can we **prevent** it? Can we **treat** it?

## It might not always be Long COVID...

Misdiagnosis: of a sample of 450 patients

- Asthma: 3
- COPD: 12
- ADHD like pattern: 5
- Alopecia with underlying cause: 2
- Depression: 23
- Anorexia: 1
- Diabetes: 13
- Sleep apnoea: 20
- Endocrine disease: 16
- Vitamin D deficiency: 21
- CCF: 13
- Anxiety: 125

# Services available in Birmingham and Solihull

Swati Shah, Clinical Lead Physiotherapist  
(Birmingham Post Covid SPA Team)

## What I'll be discussing with you

- Self Management: the resources and services available to help you manage
- The Birmingham and Solihull Long COVID rehabilitation pathway
- The role of the 'Single Point of Access' team
- About the types of patients we are seeing

# Helping you to self manage

## Self management is an important first step for lots of people

Things that you can do for yourself

- Set Realistic goals

Keep a record of,

- Your goals and what you would like to achieve
- Any changes in your symptoms
- The progress you are making towards your goals and how you feel your recovery is going
- Activity and Fatigue diaries

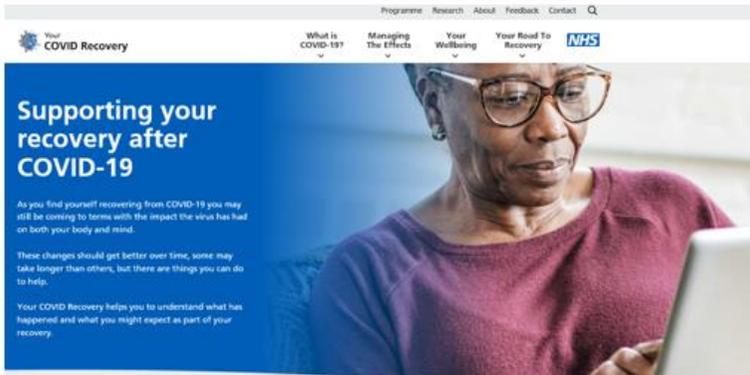
Keep a symptom diary – a symptom-tracking app can help you do this.

Know who to contact if you are worried about your symptoms are getting worst or you need more support

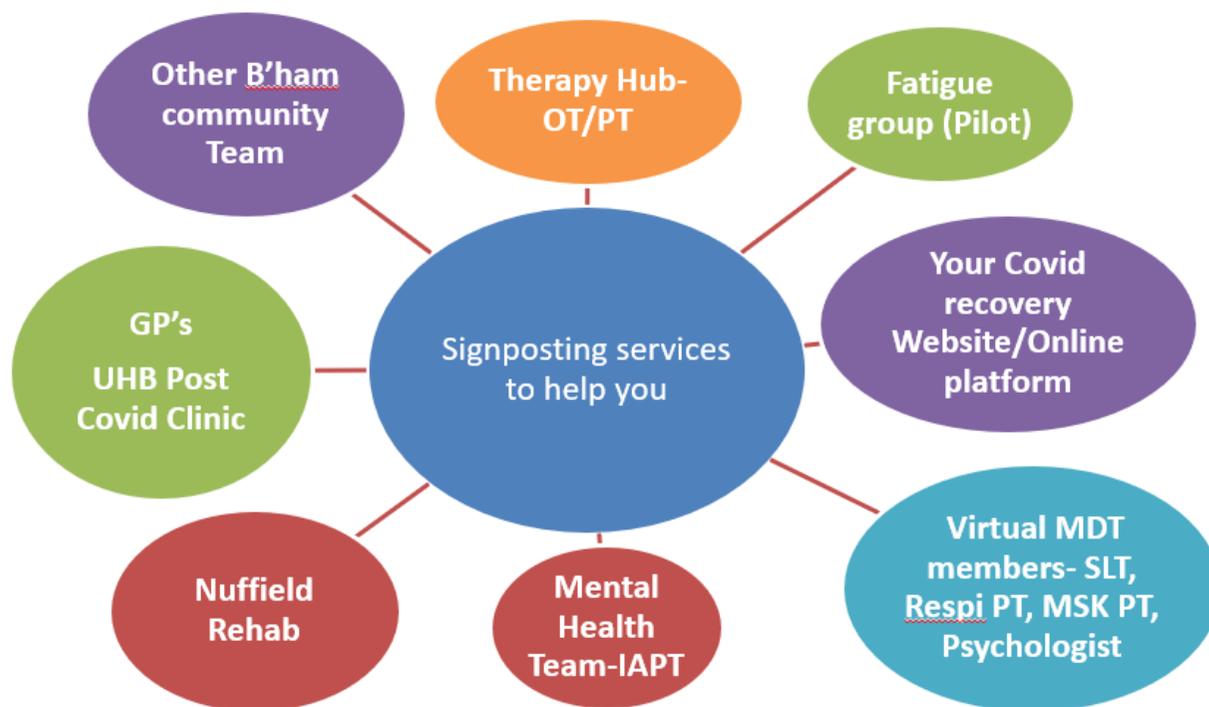
Look at further sources of advice and support your GP/other healthcare professional has made you aware. It gives information on how to get support from other services, including mental health service, social care, housing, employment, and advice about financial support. These include:

- [Open access part of the NHS website Your COVID recovery](#)
- [BSOL NHS website](#)
- [Long Covid British Lung foundation \(Breathing exercises-useful resources/ video\)](#)

# Online resources



## If you visit the GP, these are some of the resources and services available to help you



## When you go to the GP, what happens?

Visit the GP with possible Long COVID symptoms

You will have a consultation. Depending on your symptoms, you may also be offered:

- Blood test
- Chest x-ray or ECG
- Complete physical assessment
- The GP will explore whether your symptoms might point to something other than Long COVID

### Self management

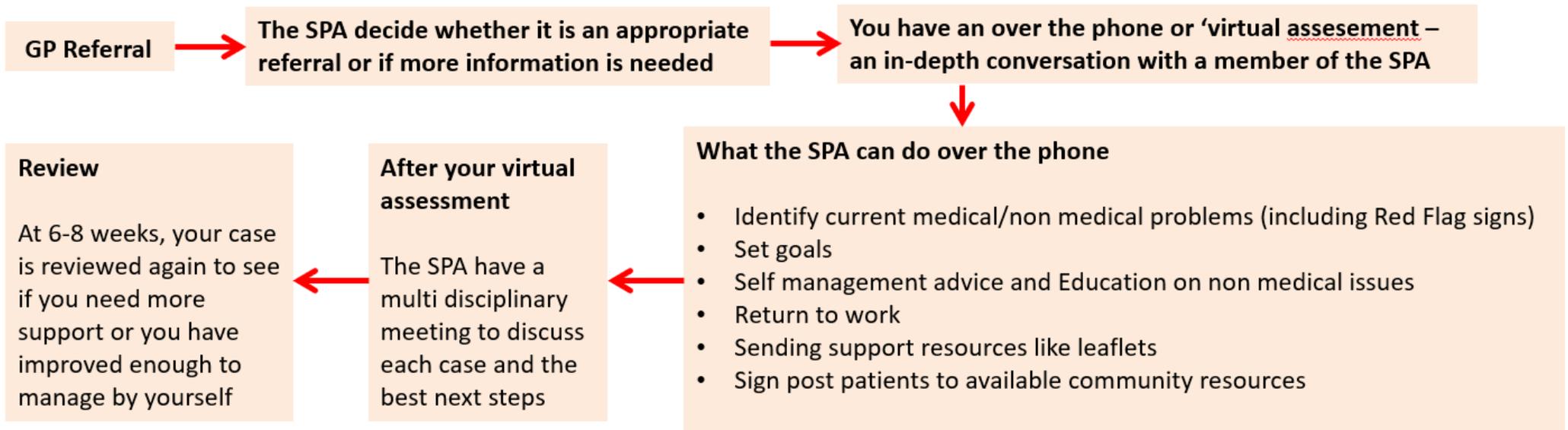
The GP supports your self management with resources

### More support

GP can refer to '**virtual BSOL post Covid SPA team**' which is available to all patients suspected to have had COVID-19.

# When you get referred to the 'SPA'

## Who is the Long COVID Single Point of Access (SPA) Team?



## Key caseload facts

- Average Age between 20 and 55 (receiving referral from 16+ age) working age group
- Pre Covid High level fitness which includes regular gym/non gym based exercises
- Not always respiratory problems previously
- Main symptoms – Fatigue, shortness of breath, cognitive problems, voice changes/mild swallowing difficulties & anxiety/low mood
- Long Haul symptoms seen in both hospital and non hospital attendance
- Autonomic dysfunction – temps / tachycardia / PoTS
- Bursts of tachycardia/palpitation happening both at rest & on exertion
- Post Viral Fatigue and lack of support at work are most common reason people not been able to return to work
- Lack of awareness of the tools to support self management

# The Post COVID Syndrome Specialist Clinic

## Dr Nandan Gautam

# The purpose of the specialist clinic

**A responsive service to identify post COVID infection and develop expertise in recognition and management of post COVID syndromes**

- A holistic approach
- ‘One stop’ (if possible)
- Patients come from both ICU and from the community
- The clinic is run by general physicians and therapists

## What patients arrive with

- Post critical illness manifestations
- Post viral pneumonia
- Post COVID
- Presumptive Post COVID

## The questions we ask

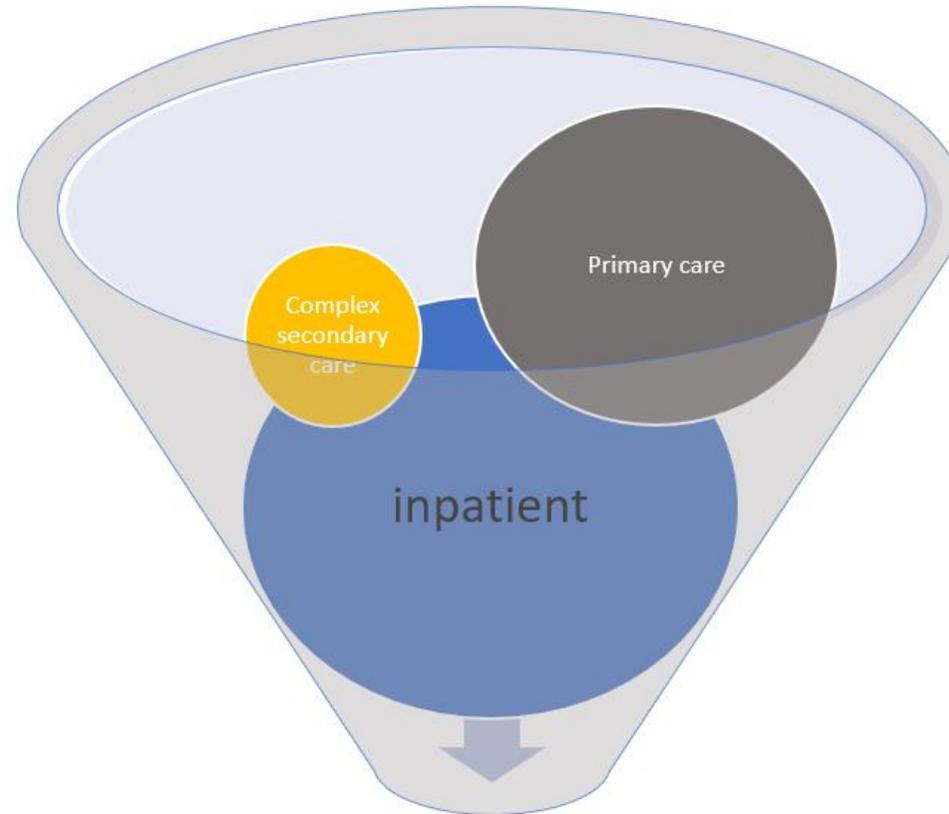
- Is this Long COVID
- Is this part of recovery
- Is this decompensation of underlying chronic disease
- Is this a new presentation of a known disease

## How we help

- Identify ongoing pathology
- Initiate investigations if needed
- Direct therapies
- Reassurance
- Acknowledge limitations

## Review, recognise, refer, reassure

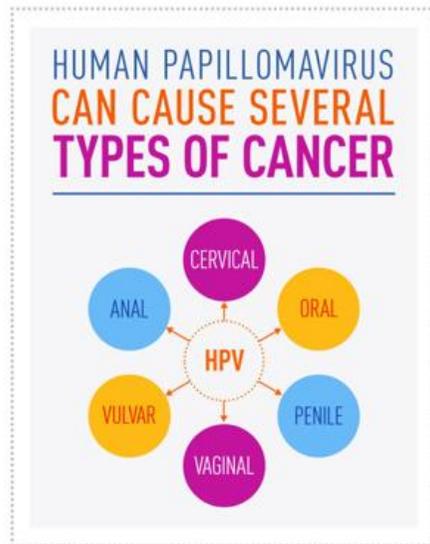
- 12-16 week recovery in 80%
- 2-5% have “something”
- 15-20% decompensation of (acute) chronic disease



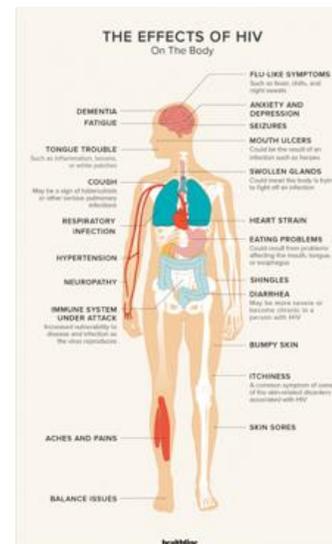
Review, recognise, refer, reassure

# We don't know everything yet, but be assured, we will learn more and we will help

## HPV



## HIV



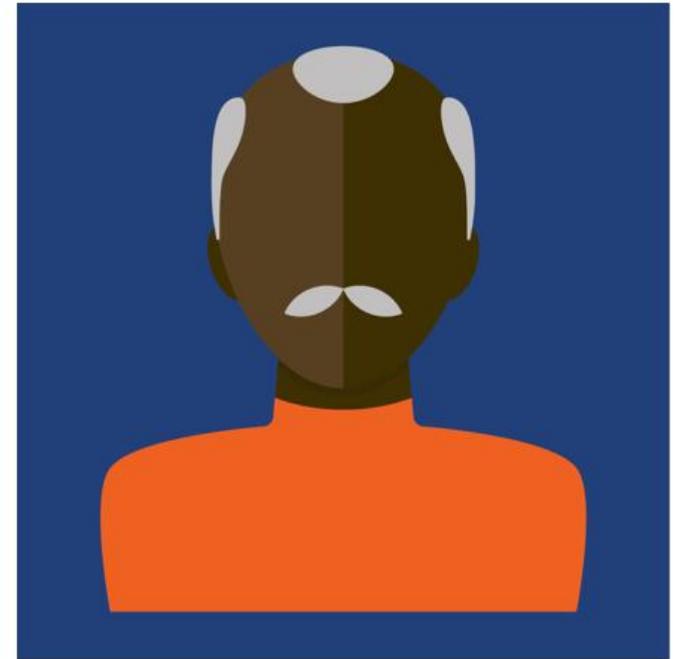
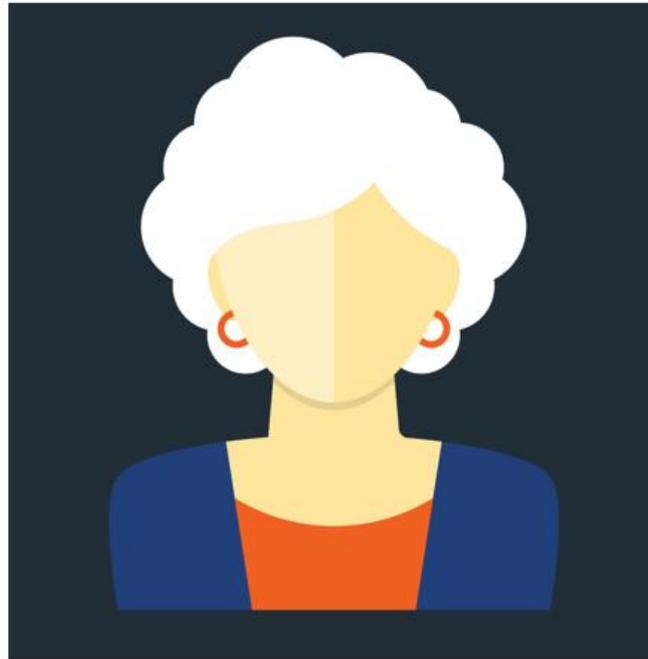
## Burkitts lymphoma

Visit your GP if you have any of these symptoms:



*Don't stop thinking about tomorrow...yesterday's gone, yesterday's gone*  
**Fleetwood Mac**

## Patient story: cases we have encountered in the clinic



# Waiting times and access

## Rebecca Lloyd

# About waiting times and mixed experiences of accessing services

## Waiting times

- We have created an entirely new service at rapid pace
- We are using health professionals who already have roles elsewhere
- We are accessing funds centrally and lobbying for more to meet the need
- We are involved in research to try and understand more and plan for the future

## Accessing services

- This is a new condition – knowledge about it is being shared so that everyone understands the best way to offer support
- We are doing lots of work with GPs to reduce variation
- We are ramping up communication to help people self manage

**We know experiences are mixed, but we are working as a system to meet the challenges and plan for the future**

# A conversation with Claire Hastie

## Living with Long COVID

- Experiences with Long COVID
- The NHS England and Improvement Long COVID taskforce

# Question and Answer Session

# Examples of self management

# Examples of self management support

## Singing Medicine

Singing has been shown to increase feelings of wellbeing

### Benefits:

- Oxytocin (feel-good hormone) is released
- Cortisol levels (known to increase feelings of stress and isolation) are reduced
- The body's natural opioids are released (which helps to reduce pain)
- The breathing techniques associated with singing aid healing and fight infection

Join the [Ex Cathedra Singing Medicine team](#) to pilot the Singing Medicine Long Covid Support group

- 3 initial sessions to explore how singing can help to improve lung function and how singing with others can improve overall feelings of wellbeing
- Led by professional vocal coaches and accompanists
- No previous singing or musical experience required!



# Thank you

We'll share this presentation with you

We will send you information about getting involved with services

## Long COVID Public Event: Questions

### Questions relating to Occupational Health

Q. Can Occupational Health refer directly to service?
<ul style="list-style-type: none"> <li>• SPA</li> <li>• UHB Clinic</li> </ul>
NO but hospital (UHB) occupational health teams can. The Single Point of Access are only accepting referrals from a GP as they require mandatory medical information to complete their assessment.
Q. As you are targeting working age individuals, how about involving Occy Health specialists?
Already involved and happy to have more if they wish
Q. Are Occy Health services involved with how someone is managed at work?
Depends on the employer but they should be whenever possible

### Questions regarding symptoms and treatment

Q. Could brain fog be seen as confusion in older adults which might be misinterpreted as early dementia?
Possible but there are specific diagnostic steps to take before diagnosing any dementia. Any significant illness can accelerate the decline in brain function. It is important to look into all differential diagnoses when it comes to confusion/brain fog through thorough questioning of symptoms and basic cognitive testing. This should ensure misinterpretation is avoided. But this must be done by a combination of the right health professionals.
Q. Is there an established link between Long Covid and post viral chronic fatigue symptoms?
Significant overlap in symptoms. Hence why long covid is not particularly helpful a term apart from conversational
Q. Until this meeting, I haven't realised my problems with swallowing might be related to Long Covid?
Might be but this should be properly looked at before making that assumption
Q. Is POTS chronic after Covid? Or will it go into remission?
Any tips for post covid POTS other than compression socks salt and water? Medication doesn't help me as it lowers my blood pressure too much.
As with most symptoms, the majority will improve and is helped by activity. The more walking and standing you do the faster the recovery. The more sedentary you are the longer it will take. Medication is not often useful for the majority.
Other ideas:

Breathing exercises, counter pressure manoeuvres, horizontal exercises- swimming/lying exercises, doing ankle-foot exercises before sitting/standing from lying/sitting position. Avoid trigger factors such as dehydration, caffeine, heat.

POTS UK website is very helpful as well.

Q. Should patients with long term covid who still have scarring on lungs and at risk of complications of pneumonia, but do not currently meet the threshold for being eligible for pneumonia vaccines (eg because of age) have the pneumonia vaccine? These patients are not being recalled by their GPs because they are not part of the annual recall? It seems the onus is on patients to ask their GPs for a pneumonia vaccine is this case?

Yes, get a vaccine

Q. Advice from doctors has been rest eat well go for walks etc. I have been doing that but have seen no improvement. I am still struggling with extreme fatigue, shortness of breath and brain fog are the main issues. I am currently off work and due to return soon I am concerned about going back as I am not up to working.

Is there anything else you can suggest treatment wise as I am unable to manage this effectively on my own? I have had these symptoms for 3 months and have gotten a positive antibody test result.

I suggest you ask your GP for a face to face consultation where other causes can be considered and then refer you to a specialist clinic. If your employer has one, contact its occupational health service also.

Try following a fatigue/activity diary with a symptoms tracker.

Build up activities very gradually while monitoring symptoms.

Please see the link below for energy conversation/fatigue strategies:

Fatigue: <https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0>

Breathing exercises:

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

<https://www.blf.org.uk/support-for-you/long-covid>

Liaising with managers re: return to work and ensuring it is at the correct pace when you feel ready for this. If you haven't mastered basics in day to day then you may not be ready.

Royal college of Occupational Therapists have some good supporting information on fatigue and return to work.

Q. I've been having long covid since March 2020 and I'm still suffering with different symptoms. When will I get better? which I know nobody know the answers too I'm on so much medication, having counselling staff wellbeing support, I've been off work since June last year I'm a Health Care Assistant at juniper Centre for older Adults. I used to be quite fit now any tasks I do I feel so tired. I'm getting some support from the long covid clinic, I feel down at times with having headaches, feeling fatigue, chest pains and brain fog, when feeling so confused at times my anxiety and depression is still ongoing not knowing when will this end

I am sorry you are having such a hard time. You are right, there is no one answer. It concerns me that you have been on lots of medications. You need to make sure other aspects of your health have been properly attended to also. There is no single pill for post covid syndromes

Q. Do you suggest if I am living with brain fatigue, extreme fatigue should I get the 3rd vaccine?  
My life is upside down.

Yes

Q. I had covid in March 2020. I had nausea and very bad diarrhoea for 10 days. Ever since I have had nausea every day and have not once had the feeling of hunger. Is it possible for Covid to affect the brain signals that tells you are hungry? I also now hate a lot of foods I used to love and can only eat tiny meals but haven't lost any weight.

Don't know about the brain affecting the GI tract aspects though that is seen in some brain injury. Sounds as if you need a face to face examination and consider an endoscopy

Q. I have read that some forms of HRT may relieve some symptoms of Post Covid Syndrome. Do the panel have any experience of this?

I am struggling with a phased return to work. I wondered if anyone knew if disability living allowance / PIP was being considered with a post covid symptom diagnosis?

How can I balance overwhelming, debilitating, fatigue and joint and muscular pain with trying to maintain a modicum of fitness?

There is a lot of cross over in the symptoms of Post Covid Syndrome and Menopause- fatigue, brain fog, aches, anxiety. Some women will have both. Many women in their 40s and 50s will have Post Covid Syndrome and menopausal symptoms can be worsening their experience. HRT will help menopausal symptoms and in women with both conditions will relieve some of the symptom burden.

Research is still needed to establish how Covid impacts on hormones and the menstrual cycle. It is important to remember HRT is not for everyone and comes with its own risks and side effects. My Menopause Doctor is an excellent website for patients and professionals and keeps up to date with developments.

Figures from DWP show that by April 2021, there were 2,705,857 people across the nation claiming PIP for a long-term illness, disability or mental health condition - including 288,135 in Scotland.

However, included in those statistics are 20 claimants from England and Wales who are now receiving PIP with long-Covid attributed as their main disabling condition.

There is a massive backlog of applications so these numbers will rise

Q. I've had Long Covid for well over a year now having had a 'mild' case of Covid before the first lockdown. I have found it very difficult to get any support. I am now awaiting an appointment but wonder if there is anything I could be doing to prevent the constant exhaustion and to rebuild my strength?

A number of online self-help resources are available: [Postcovidsyndromesol.nhs.uk](https://postcovidsyndromesol.nhs.uk)

Please follow a fatigue/activity diary with symptoms tracker.

Look at your new baseline then build up activities very gradually while monitoring symptoms.

Please follow the link below for energy conversation/fatigue strategies:

Fatigue: <https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0>

Q. Was there follow up with patients to see if they experienced post exertional symptom exacerbation?

Within our rehab teams yes and within our specialist respiratory physio clinics yes.  
Very few experienced exacerbation when used with an activity diary.

**Q. Has Physio been using Buteyko breathing techniques?**

Not that I've heard of. The more complex dysfunctional breathing patterns and respiratory presentations are referred to the specialist respiratory physios who carry out their own assessments and monitor patients 1:1. They haven't mentioned this approach. We are having to be careful with hyperventilation in a lot of patients we are finding so prescription is very much individually biased for this.

**Q. Are people really getting better or are they relapsing and not able to access the service again?**

We asked the first 100 of our patients after 12 months and physically saw anyone who felt they still had problems. Of all of these 5 had ongoing problems.

Most are getting better. Some do experience relapses but from my personal caseload there have been very few.

When patients are discharged from the Birmingham Single Point of Access service, we do advise patients to speak to their GP if they require further input later on and if the GP feels it is needed, they can re-refer to our service.

## Questions regarding access to service

**Q. Average time before seen in clinic?**

For Birmingham Single Point of Access team, it's average 10 weeks. However, we are working on reducing this waiting time.

**Q. How long from referral to being contacted- virtual or face-to-face?**

Currently it is 62 days.

**Q. Do you need to register to get a triage call?**

Yes – through GP into pathway.

**Q. I was told I couldn't be referred to respiratory physio if I had further relapses because I don't have a pre-existing lung condition- is this still the case?**

You will need to have a face to face review.

There are some elements of respiratory physio where you need a pre-existing lung condition – this is something we are looking into. However it does tend to be for the pulmonary rehab style approaches and we know that this isn't suitable for COVID alone. So no it shouldn't be the case unless there is some information we are missing in this situation.

**Q. Do I need to get my GP to refer me into the clinic?**

Yes, referral is required to the clinic and the Single Point of Access

## General Questions

Q. Have people with Long Covid been involved in developing services?

Yes, we have recently completed a fatigue pilot group and we are using the 'Friends and Family' Test to get patient's feedback to improve our services.

Q. It seems children can get Long Covid- what is the support for them? Advice and information for their understanding? Advice for schools and teachers please?

From August 23rd Birmingham Children's Hospital (BCH) begin accepting referrals for its new Paediatric Long Covid Assessment Service, serving patients and professionals across the West Midlands.

One of 15 new paediatric hubs across the country, the service is designed to assess patients experiencing long-term health effects following COVID-19 infection. While it appears young people have been less severely physically impacted at the infection stage, with a much lower level of hospitalisation compared to those older, there have been numerous reports of children experiencing the same or similar Long COVID symptoms to adults such as fatigue, difficulty concentrating and mobility issues. The multi-disciplinary service at BCH will assess and make recommendations as to the best course of treatment and support.

Referrals will only be accepted from either hospital or community-based paediatricians.

It also remains important to signpost young people and families to the [Long COVID Self-Help information available on the NHS website](#).

GPs will **not** be able to refer directly into the service and parents will **not** be able to self-refer their child.

However, parents are encouraged to make an appointment with their GP in the first instance if they are worried their child may be exhibiting potential Long COVID symptoms, which may require assessment by a local paediatrician and/or subsequent referral into the Paediatric Long Covid Assessment Service as appropriate. For Long COVID to be diagnosed, symptoms should have continued for at least 12 weeks after the original infection and other causes of those symptoms considered and excluded.

Assessment will take place through multi-disciplinary team meetings where experts come together to review a child's history and current symptoms. In some circumstances, clinic-based face-to-face assessment will be necessary, and some virtual/video appointments may also be offered.

The clinical team will advise families, local hospitals, and clinicians on how best each child's symptoms could be managed. BCH will not provide treatment for all the children assessed, except where it would ordinarily be the child's local hospital; instead, the intention is for children to receive any treatment they need as close to home as possible, normally through their own district general hospital or associated community service.

Q. Are Long Covid symptoms more severe or longstanding in people who weren't vaccinated?

The majority of people who have persistent symptoms hadn't been vaccinated.

Q. Is Long Covid classed as a disability?

Patients are reporting to us that they are being told it is not. In the absence of any Employment Tribunal ruling and the evolving nature of Covid-19, there is currently no definitive answer to whether 'long Covid' satisfies the statutory definition.

However, at an Occupational Health Educational Update this week they were in no doubt that it is, if the requirements of the definition are fulfilled:

- 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.

There is no need for a condition to be officially recognised or diagnosed for it to be found by a tribunal or court to be a disability.

'Long term' means the impairment has lasted or will last for at least 12 months

As it stands, whether long Covid will meet the threshold of a disability will be determined by Employment Tribunals looking at individual cases. On the back of this uncertainty, the Trades Union Congress (TUC) has called for urgent recognition of 'long Covid' as a disability and Covid-19 as an occupational disease. Whether any particular person suffering from long Covid symptoms is protected will depend on the specific impact on that person and would need to be considered on the facts on a case-by-case basis.

Q. Can you get COVID again if you have had it before and have long Covid?

Yes

Q. How does the advice differ to me/ CFS and how is this impacted by the delayed NICE guidelines?

Very similar. Lots of guidance being taken from ME/CFS. Delay in NICE guidance isn't impacting our clinicians that I am aware of. We treat everyone as individuals and the important thing is working with your symptoms/baseline and managing from that point.

Long COVID isn't one thing. It is better described as an overlap of many syndromes that affect different people differently.

Q. Is there data/projections of COVID patient Cohorts in the UK:

- Total Cases
- Deaths
- Hospitalised
- Long Covid Sufferers?

Yes. NHSE website

## Resources

- *PACE-ing Your Way to COVID Recovery” - Physical Therapy experts on the P.A.C.E.R. Project (Post-Acute Covid-19 Exercise & Rehabilitation)* - [https://www.youtube.com/watch?v=lnxn2AEsBo&ab\\_channel=SurvivorCorpsHQ](https://www.youtube.com/watch?v=lnxn2AEsBo&ab_channel=SurvivorCorpsHQ)
- <https://www.survivorcorps.com/webinars>
- <https://www.longcovidkids.org/>
- <https://www.som.org.uk/covid-19-return-work-guide-recovering-workers>
- <http://gh.bmj.com/cgi/content/full/bmjgh-2021-005427?ijkey=9fQpn8SAJ9CSohP&keytype=ref>
- <https://www.longcovid.org/resources/patients#work-benefits-and-finances>
- <https://www.youtube.com/watch?v=LmjJ2yuhT-o>
- <https://www.survivorcorps.com/pccc>
- [https://spiral.imperial.ac.uk/bitstream/10044/1/89844/9/REACT\\_long\\_covid\\_paper\\_final.pdf](https://spiral.imperial.ac.uk/bitstream/10044/1/89844/9/REACT_long_covid_paper_final.pdf)
- [@LongCOVIDPhysio](https://twitter.com/LongCOVIDPhysio)
- <https://twitter.com/LongCOVIDPhysio/status/1435470501544087557/photo/1>
- <https://www.yourcovidrecovery.nhs.uk/>
- <https://www.longcovid.org/>
- [Singing Medicine - Adults affected by Long Covid - YouTube](#)

## Energy Conservation

Association of Chartered Physiotherapists in Respiratory Care

Leaflet No. GL-03

Page 1



# Energy Conservation

People with lung problems often get short of breath or tired, or both, doing daily tasks such as getting dressed or doing jobs around the house.

Energy conservation is conserving (saving) your energy. It means finding the easiest way of doing the everyday tasks you have to do, so that you have some energy left over to do the things you would like to do. Learning to use the ideas in this leaflet will help you to do this.

It is important to remember that conserving energy is not about avoiding exercise. Energy conservation is about making everyday tasks easier and it will allow you to have some energy left for exercise. Exercise is important to increase your fitness and improve your health. Being fitter will help you manage tasks and chores more easily.

To help you control your breathing doing these everyday tasks you can also learn and use the breathing exercises in leaflet GL-02.

Remember to take rests before you get too short of breath. You can rest in one of the positions in leaflet GL-01 to help you to recover during activity.

### **How do I conserve energy?**

The following ideas to conserve or save energy can be used for any activity or task:

- Plan ahead
- Avoid the Boom-Bust Cycle
- Pace yourself
- Use breathing exercises
- Sit during tasks and activities
- Minimise arm movements
- Avoid bending, reaching, twisting
- Use good posture
- Use good body mechanics

### **How do I plan ahead?**

**Your week:** Think about all the tasks you need to do during the week ahead. Spread your tasks throughout the week, rather than doing them all in one day. Try to avoid having two very busy days together.

**Your day:** Spread heavy and light tasks throughout the day. This allows you to recover your energy after a heavier task. Then you will have some energy left to do other things.

Do the heavy tasks when you are at your best in the day. For example, if you have more energy in the morning, do your biggest or hardest tasks then. Avoid heavy jobs when you are tired.

**Each task:** Gather all the items you need for a given job; for example, ingredients, utensils, pots and pans for preparing your meal or your clothes before starting to get dressed. Then take a rest before starting the task. This allows you to recover your energy so you have some left to do the task.

### **What is the “Boom-Bust Cycle”?**

The boom and bust cycle is peaks of over-activity (the boom) and troughs of under-activity (the bust).

For example, on a good day when you have more energy, it is tempting to do all the jobs or activities that you have put off before. If you do this, you may do more than your body is used to. As a result you can experience fatigue and tiredness and feel more short of breath. This leads to the ‘bust’ phase, where you have no energy. To recover from this ‘bust’ phase you are forced to rest, sometimes even for a few days.

After a few days rest, you feel better and start the over-activity again and so this harmful cycle goes on. But as time goes on ►

## Association of Chartered Physiotherapists in Respiratory Care

Leaflet No. GL-03

Page 2



► you are able to do less and less even on the 'boom' days and the 'bust' periods last longer. This is because each period of under-activity ('bust') results in a drop in fitness.

### ***How do I pace myself to conserve energy?***

Pacing to conserve energy is the opposite of the Boom-Bust cycle. It is learning to recognise how much you can do and at what speed, so that you avoid exhaustion. You learn to pace yourself and take enough rests. By slowing down, or stopping to rest before you are exhausted, you will be able to continue or restart the activity, and you will find that you can carry on for longer. It also means you won't need to rest for as long, because you are not as tired when you do stop to rest. Hurrying may have always been part of your life but trying to use these pacing tips may help you to do more. Pacing requires practise and it can be hard changing lifetime habits.

Pacing is especially useful when you are breathless or tired, and so how often and when you use these tips will vary from person to person. Most people find that pacing is especially helpful when they are unwell, and many use it all of the time. Practising when you are well can make it easier to use when you are unwell.

Keeping to a moderate, steady pace during tasks and activity allows you to be most productive. For example, don't rush to get to the top of the stairs, pace yourself to leave some breath for when you get to the top. You should plan rest periods throughout the day, such as a short rest period every hour. This will help you to conserve your energy and keep going for more of the day. Some helpful tips are:

- Avoid fatigue
- Get enough rest
- Do not wait until you are tired before you stop and rest
- Try to have a rest or lie down for a short time in the afternoon to recover some of the

energy used during morning activities

- Avoid hurrying or rushing
- Avoid large meals
- Avoid activities for 1 hour after meals

### ***How do I do breathing exercises?***

Use the exercises in leaflet GL-02 to help you. Ask your physiotherapist to provide this for you. If you have been taught pursed lips breathing or 'blow-as-you-go' you can use these during activities. Do not hold your breath - When in doubt, breathe out!

Have adequate ventilation in your home-cooking odours, cleaning products and humidity can make breathing more difficult. Avoid aerosols and sprays; for example, try using a damp cloth to dust.

### ***Why should I sit during tasks and activities?***

Sitting uses less energy than standing. For example, try sitting in the bathroom when washing or drying yourself. Having a seat in the shower can be helpful. Sitting down for a simple task such as to prepare vegetables for a meal can also help you to save your energy.

### ***How can I minimise arm movements?***

This is especially important for tasks above shoulder level. Try to keep your elbows as low as possible and close to your body. For example, rest your arm against your chest as you clean your teeth. If you can, support your elbows on a surface when working in one place, for example, when preparing vegetables, or shaving, brushing your teeth or combing your hair. See leaflet GL-01 for positions to reduce breathlessness. Use a towelling robe instead of rubbing yourself dry with a towel. For activities or tasks above your head, try to break the activities down into smaller sections, and have a rest between each section. Breathe out when you lift your arms ►

## Association of Chartered Physiotherapists in Respiratory Care

Leaflet No. GL-03

Page 3



### ► **How do I avoid bending, reaching, twisting?**

Organise your things so that they are within reach. Instead of twisting, move your feet to turn your body. If you do have to bend, reach or twist, breathe out as you do it. Use long handled equipment for reaching for example a 'helping hand' to pick things up from the floor or a long handled sponge to wash your feet.

### **How do I use good body mechanics?**

The way that you do an activity can make it easier or harder. Good body mechanics can help you to make tasks easier. For example if you need to move something, it is easier to push or pull it rather than lift it. Pushing is usually easier than pulling. If you need to move something in the kitchen you can slide objects along a counter rather than lifting or carrying them.

If you do have to lift something, bend your knees and use your leg muscles rather than bending your back, and stand close to any objects to be moved. This will help you to use the stronger muscles in your legs to do the work and will also be better for your back.

If you have been taught 'blow-as-you-go' you can use this when you have to lift or move

objects. For more information see leaflet GL-02 – ask your physiotherapist to provide this for you.

**If you would like more help or advice with energy conservation, ask to see a physiotherapist or Occupational Therapist.**

### Useful contacts

Association of Chartered Physiotherapists in Respiratory Care  
[www.acprc.org.uk](http://www.acprc.org.uk)

British Thoracic Society  
[www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)

British Lung Foundation  
[www.lunguk.org](http://www.lunguk.org)

Chartered Society of Physiotherapy  
[www.csp.org.uk](http://www.csp.org.uk)

Asthma UK  
[www.asthma.org.uk](http://www.asthma.org.uk)



## Fatigue and post-exertional symptom exacerbation

# 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, inappropriately high heartbeat (tachycardia), and/or chest pain.

**Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.**

## Activity Diary

### **Fatigue Diary**

#### **Guidelines for completion:**

- 1. At the top of the day's diary, describe how you slept the night before.**
- 2. Assign a number value from 1 to 10 (1 being very low and 10 being very high) for your level of fatigue.**
- 3. Describe the activities you carry out during the day (e.g., stood in shower 10 minutes)**
- 4. List under comments all symptoms as they appear or worsen during the day (e.g. if legs feel heavy, if pins and needles increases)**
- 5. Make notes on activities as often as you can.**

**It is recommended that the diary is completed over 3-7 days to gain a better understanding of your energy levels over a period of time**

## Activity Diary

Date \_\_\_\_\_

Please also make a note of the quality of your sleep the night before

**Sleep:** (e.g. hours slept, how many times woken up, why, quality e.g. poor, good etc.)

Time	Activity	Scale of fatigue 0= no fatigue 10- severe fatigue	Symptoms
E.g. 08:00	Made breakfast (15 mins)	8	Short of breath + nausea