Long Covid Rehabilitation Booklet

An Information Guide



University Hospitals Plymouth NHS Trust



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Introduction

This booklet has been designed to provide you with information on Long Covid and what you can do to help manage your symptoms and support your rehabilitation.

COVID-19 is an infection caused by Corona Virus, which can last for up to 12 weeks. Long Covid is a term used to describe symptoms which continue to last beyond 12 weeks and are not explained by an alternative diagnosis.

An estimated 1.8 million people living in the UK are experiencing self-reported Long Covid symptoms and 67% of these stated it affected their day-to-day activities (1).

Common Symptoms

There is a wide variety of symptoms experienced by individuals experiencing Long-Covid with the most common being (2):

- 1. Fatigue
- 2. Breathlessness
- 3. Cognition (Poor concentration and brain fog')
- 4. Chest pains and palpitations
- 5. Muscle and joint pain
- 6. Loss of sense of smell and taste
- 7. Anxiety and depression

Please seek advice from your GP or call 111 if you feel your symptoms are worsening and might need further investigation.

Thinking patterns and symptoms

Having COVID-19 in the first place can be very frightening and it is understandable that the continued symptoms even months after can have a huge physical and emotional impact.

However, it is important to realise that worrying and thinking about your symptoms can make them worse. For example, if you focus on your breathing for a few minutes you will feel the sensations more.

You will experience good and bad days throughout your recovery, and it is important not to focus on the negative. Try to stay positive, be kind to yourself and invest time into the activities that you enjoy- or even try new ones! (3)

We recommend reading the whole booklet, even if you are only struggling with one specific symptom as most of the management plans are holistic in improving multiple areas.

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Fatigue

What is fatigue?

We are all familiar with the physical feeling of fatigue after exercise or the mental fatigue after long periods of concentration.

However, with Long Covid, fatigue can be felt in a way that does not seem normal. Despite resting, and a good night's sleep, fatigue occurs after minimal effort, is prolonged and limits your usual activity. It can leave people feeling dull and finding it difficult to concentrate and recall memories.



Common exacerbations of fatigue in Long Covid:

- Low levels of physical activity
- A disturbed daily routine
- Poor sleep patterns
- Demanding work
- Caring responsibilities
- Low mood
- Anxiety and stress

Management of Fatigue

Try following the **3 P's Principle – Pace, Plan and Prioritise** – to conserve your energy when going about your daily activities.

- Spread activities out over the day by prioritising what needs to be done.
- Take frequent breaks to avoid an over activity/under activity cycle.
- Try not to talk and move at the same time.
- Give yourself time to recover your breath and conserve your energy for the task.

Pace:

Fatigue and other Long Covid symptoms can affect your ability to complete everyday activities, such as getting washed and dressed, and doing tasks around the home. Activities that are usually simple might seem like hard work, and you may feel that you have less energy than usual.

There are lots of simple things you can do to help yourself. Getting enough sleep and making sure you eat well will both help. It is important to conserve your energy when you are completing your everyday tasks to help make sure that you have enough energy throughout the day.



Plan:

Plan each day in advance so that you can do what you need and consider what can be delegated to other people. Build a regular routine and try to avoid 'boom and bust' behaviour, where you are very active on 'good' days and then feel exhausted the following day. An activity diary can help with this.





Prioritise:

You can also decide which activities that you are doing are most important to you. If this is a task which is very important, prioritise and do it when you have the most energy. If they are not important, but 'have to be done' can you delegate them?

Think about areas where you can save energy and **delegate** tasks, for example, online shopping rather than a trip to the supermarket, or cooking at the weekend for the week ahead when you are busy. Finally, make sure you are doing some things which are enjoyable, such activities can be energising.





Fatigue feels much worse if your sleep pattern is also disturbed so try and get a good night's **sleep**.





Energy levels are also helped by **staying active**. Being unfit makes you more tired. Once the amount of activity you are doing is stable, try to increase the amount you do slowly and gently.





Relaxation:



Relaxation techniques can help with fatigue and energy conservation as they promote a good sleep pattern and can help reduce stress. Consider trying techniques such as: mindful meditation, aromatherapy, yoga, tai chi, and other activities you find relaxing, such as reading or having a long shower or bath.

While regular exercise is important, you should also take some time to relax both your mind and body.

Stress and anxiety is not uncommon after illness, it can:

- increase both your heart rate and blood pressure
- interrupt your sleep cause low mood which may affect your ability to resume your normal day to day routines.

Guided imagery is a technique which involves mentally visualizing a place in your life that represents safety, comfort or happiness.

Places may include a garden, a beach or a house. You can practice some deep breathing exercise during this.

Your body has been through a lot, so it is important you make time for yourself regularly. It does not take very much time and regular practice can dramatically reduce your stress levels. Some good examples of mindfulness can be found on 'Every Mind Matters' on YouTube, Headspace from the app store or Be Mindful is an online course.

Doing things that you enjoy is a great way to relax. This may include:

Listening to music

Drawing or doing something creative

Reading a good book

Yoga

Sitting in the garden



Explain to your family, friends, and colleagues at work the impact the fatigue is having. Because fatigue is invisible, sometimes it is not properly understood. Until it is experienced it can be hard to understand the impact of fatigue and how debilitating it can be.

For further information, please refer to:

Your COVID Recovery | Supporting your recovery after COVID-19

Breathlessness

Breathlessness is a common symptom reported by individuals with Long Covid. Following the initial infection your lungs can become irritated, increasing your work of breathing. With Long Covid, breathlessness can often be associated with deconditioning and anxiety.

Over-Breathing/Hyperventilation is a perfectly normal reaction to any stressful situation. Generally, when this has passed your breathing will return to a normal rate.

You may experience:

- -Feeling breathless, even after relatively mild exercise
- -Difficulty co-ordinating breathing and talking and/ or eating
- -Breathless when anxious or upset
- -Pins and needles in hands / arms / around mouth
- -Palpitations
- -Feeling exhausted or unable to concentrate
- -Light headedness

Management of Breathlessness









Positioning:

The muscles you use to breathe are the same muscles that support your shoulders and neck. These positions help to support your shoulders so that your muscles can be used solely for breathing.













- 1. Lie or sit comfortably. Place one hand on your stomach and the other relaxed by your side.
- 2. Close your mouth lips together and keep your jaw loose.
- 3. Breathe in gently through your nose, feeling your tummy rise and expand 'like a balloon'
- 4. Breathe out lightly through your nose if possible, keeping your stomach relaxed
- 5. Make sure you are relaxed, pausing at the end of each breath. Your upper chest should not be moving.
- 6. As you repeat this sequence be aware of any areas of tension in your body and concentrate on 'letting go' particularly jaw, neck, shoulders and hands.

Practise this little and often. Progress this to practising whilst standing or walking. As your body adapts to this way of breathing it will require less time and energy and is more relaxing.

BORG Breathlessness Scale

Use this scale to monitor your breathlessness during any activity or exercise.

You should be aiming to work at a score of 3-4

It is normal to feel breathless when you exercise. It is not harmful or dangerous.

Gradually building your fitness can help you to become less breathless.

0 0.5 1	Nothing at all Very, very slight (just noticeable) Very slight	
2	Slight	
3	Moderate	
4	Somewhat severe	
5	Severe	
6		
7	Very severe	
8		
- 2	Very, very severe (almost maximal)	
9		



Exercises

You may feel tired but even some basic exercises will be beneficial to your recovery. Start with 6-8 repetitions of each activity; gradually increase up to 12 repetitions. Getting out into a chair will greatly benefit your lungs, muscles, circulation and digestive system.















CHAIR:



March your legs while sitting



Straighten one knee at a time and hold



Cross your arms and turn your head and body left and right.



Bend your arm to touch your shoulder, and then straighten.



Lift your arm up above your head then lower.



Keep your elbows tucked in, move your arms in and out.



STANDING:

Hold onto a firm surface for all standing exercises, for example, a kitchen work surface. Not all exercises need to be done at once so break them down into manageable sessions.



Lift the leg out to the side, and back to the centre.



Stand up on your toes and gently back down.



and back to the centre.





hands if you need to)



For further information, please refer to:

https://www.plymouthhospitals.nhs.uk/covid-rehab-physiotherapy



Goal Setting

Setting goals is a great way of taking back control if you're struggling with Long Covid. They are a helpful tool in noticing and recording the progress you make over time, in turn increasing your motivation, self-confidence and focus.

SMART Goal Setting:

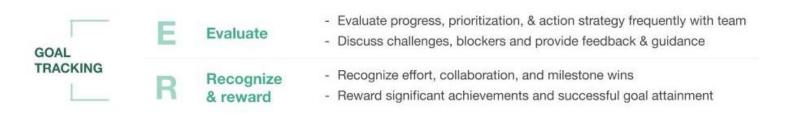
SMART goal setting is a way of ensuring you get the best chance of achieving your targets.

SMART is a format of structuring your goals to make sure they are:



How to track your goals:

Once you have set your goals, you have not finished. It is crucial to track your progress by:





Cognition

Cognition is the ability to clearly think, learn and remember. It is an important component of performing everyday activities. (4) People with Long Covid can experience a range of difficulties with these abilities.

The brain is endlessly:

- Perceiving
- Processing
- Planning
- Organizing
- Remembering



It is always active, yet we don't notice most of our brain's activity as we move throughout our daily routine. Put simply, cognition is **THINKING**.

Our brain acquires processes and uses information from our senses, knowledge and experiences. Cognition encompasses the skills listed below:



Cognitive impairment is one of the three most common persisting symptoms six months post COVID so it is important to be aware (1)



Brain Fog:

A common reported symptom of Long Covid is Brain Fog. Brain Fog is not a medical term but used to describe a range of symptoms such as:

- Poor concentration
- Feeling confused
- Thinking more slowly than usual
- Forgetfulness
- Difficulty with word-finding

Brain Fog is often made worse by fatigue, meaning the more tired a person is, the more they notice increased difficulty with their thinking skills (5)



Management of Cognition

- Minimise distractions: working in a quiet environment with no background distractions
- Complete activities when less fatigued: refer to the 3 P's on page 4.
- Say things out loud: to ensure you stay on the right track
- Take frequent breaks: use "little and often" as a guide and pace yourself
- Set yourself targets or goals: Having something definitive to work towards will help you stay motivated. Refer to goal setting on page 12.
- Use incentives: when you achieve a target or goal reward yourself, even if its something simple such as a cup of tea or coffee.
- One thing at a time: concentrate on one thing at a time, do not try to take in too much information at once.
- Don't rush things
- Use of aids: such as lists, notes, diaries and calendars can all help support memory and routine.



So overall.....

- Be aware of the impairments you have and how they impact you and your daily life.
- Share the difficulties you are having with others and ask for /accept support
- Keep active and continue as far as possible with your usual daily activities/routines/roles (adapted to suit you).
- Use **remedial activities to stimulate and challenge** your cognition: cards, board games, brain training, word searches, cross words, Sudoku.

BE AWARE OF OTHER IMPACTS ON YOUR COGNITION... Fatigue, fear, stress, anxiety, low in mood and altered sleep patterns all take their toll on our ability to think clearly.

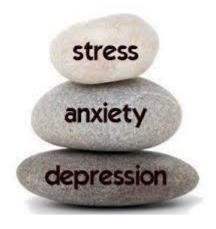
For further information, please refer to:

https://www.plymouthhospitals.nhs.uk/covid-rehab-occupational-therapy

Emotional and Psychological Impact

Many people who are struggling with Long Covid can often experience symptoms of anxiety or depression. These may include:

- feeling restless or on edge, being irritable, feeling anxious or worried.
- flashbacks, nightmares, repetitive and distressing images or sensations.
- irritability, angry outbursts, feeling intolerant of others.
- continuous low mood or sadness, feeling tearful, feeling hopeless and helpless.
- having low self-esteem, feeling guilt-ridden.
- having no motivation or interest in things, not getting any enjoyment out of life.
- having suicidal thoughts or thoughts of harming yourself, feeling like you are not connected to your body, a feeling of dread or a fear of dying.





Feeling anxious or depressed also include physical symptoms (it is often difficult or impossible to decide if these symptoms have a physical or an emotional cause or a bit of both). Symptoms may include:

- a racing heartbeat, feeling faint, sweating, nausea, chest pain, dizziness, numbness or pins and needles.
- shortness of breath, a choking sensation, dry mouth.
- trembling, hot flushes, chills, shaky limbs, having tense muscles.
- a need to go to the toilet, a churning stomach.
- ringing in your ears, a tingling in your fingers.
- having difficulty getting to sleep or staying asleep.
- difficulty concentrating, finding it difficult to make decisions.

In many ways feeling anxious or low is a normal part of recovery from an illness but if you find the symptoms do not reduce, or if they cause you distress, or interfere with your ability to recover and get back to life, help is avail

Top tips to cope with anxiety



Understand your anxiety

Try keeping a diary of what you are doing and how you feel at different times to help identify what's affecting you and what you need to take action on.



Challenge your anxious thoughts

Tackling unhelpful thoughts is one of the best things we can do to feel less anxious. Watch the video to find out more.

Reframing unhelpful thoughts video



Make time for worries

Tackle your worries video

If your worry feels overwhelming and takes over your day, setting specific "worry time" to go through your concerns each day can help you to focus on other things. Watch the video for more advice.



Shift your focus

Some people find relaxation, mindfulness or breathing exercises helpful. They reduce tension and focus our awareness on the present moment.

Try NHS-recommended relaxation exercises



Face the things you want to avoid

It's easy to avoid situations, or rely on habits that make us feel safer, but these can keep anxiety going. By slowly building up time in worrying situations, anxious feelings will gradually reduce and you will see these situations are OK.



Get to grips with the problem

When you're feeling stressed or anxious, it can help to use a problem-solving technique to identify some solutions. This can make the challenges you're facing feel more manageable.



Speech, Swallow and Smell

Speech:

You may experience changes to your voice, similar to when you experience a cold.

Tips for your vocal recovery:

- Keep well hydrated
- Try a gentle steam over hot water
- Avoid deliberate throat clearing
- Use your normal voice
- Avoid smoking or vaping

Swallow:

You may find your favourite foods taste and smell differently following your COVID illness. Food may taste bland, salty, sweet or metallic. It is important to choose foods that appeal to you to ensure you eat well, but continue to retry foods as your taste preferences change.

Some people are experiencing changes to their swallow. Some signs to look out for are:

- Coughing and throat clearing when eating and drinking
- Recurrent chest infections
- Having a wet, bubbly voice when eating or drinking
- Difficulty managing secretions

Smell:

If you are deliberately paying attention to a smell you are truly in the present moment. Try to find a smell that has positive associations for you – maybe one that reminds you of happy times, or a smell which you enjoy. Use it to bring yourself back to the present moment.

Helpful smells

- Small bottles of essential oils e.g. eucalyptus, mint, lavender, lemon
- Small dried flowers such as lavender
- Perfume soaked on a tissue
- Whole spices from the kitchen



For further information, please refer to:



Nutrition & Hydration

To help support your body in fighting Covid-19 virus it is important to ensure you have good nutrition and hydration even if you've lost your appetite and don't feel hungry! This helps rebuild your muscle strength and function as part of your rehabilitation.

Below is some general information to help promote good nutrition and hydration. If you have specific dietary requirements, please check with a healthcare professional that the information is safe for you to follow.

Hydration:

- Getting enough fluid is essential for good health and you may need more than usual if you have any infection.
- Adults are usually advised to drink 6-8 mugs or large glasses a day but this may need to be higher if you have a temperature, during warm weather or if you are experiencing loose stools. Nourishing drinks such as milk, soup or fruit juice can help meet your fluid needs.
- Ensure when exercising you have a bottle or cup of water with you

Nutrition:

- Eat 'little and often' aim to eat every 2 hrs by having up to 5-6 small frequent meals, snacks or nourishing drinks during the day rather than 1-2 large meals.
- Try not to have drinks just before meals to avoid feeling too full to eat.
- Avoid low fat/diet versions of food and drinks for example skimmed or semi-skimmed milk, low fat yoghurt, or watery soups (e.g. cup a soup) and go for creamy, milky nourishing alternatives unless been advised not to do so.
- Choose meals that you enjoy, are easy to prepare, and are high in energy and protein. Fortify these foods where possible.
- Choose easy to chew, moist foods that are easier to swallow (e.g. casseroles, curries, sauces, gravy, milky puddings, fruit smoothies, ice creams).





Supplements:

<u>Vitamin D</u> is needed for bone and muscle health, as well as immunity. A daily vitamin D supplement of 10 micrograms or 400IU is recommended for all UK adults from October to April. If you have little or no sunshine exposure because of Long Covid, and are spending most of your time indoors, you should take the supplement all year.

<u>Vitamin C</u> is an antioxidant that helps protect your cells against the effects of an infection and has many important functions. Adults require 40 micrograms daily, which you should be able to get by eating a varied and balanced diet. (6)

If you are only eating small amounts, or are unable to eat well, you risk a low intake of vitamins and minerals. You may wish to take a one-a-day A-Z multivitamin and mineral supplement, of no more than 100% recommended intake (7)

For further information, please refer to:

https://www.plymouthhospitals.nhs.uk/covid-rehab-dietetics https://www.malnutritionpathway.co.uk/covid19-resourcetool



Cardiac Symptoms

Dysautonomia is an umbrella term, that refers to a problem with the autonomic nervous system. When the autonomic nervous system does not function properly, people may have trouble with the regulation of heart rate, blood pressure, body temperature, and perspiration, which can be triggered by a bacterial or viral infection such as COVID-19

Some common symptoms include:

- Light headedness
- Dizziness
- Fainting
- Rapid heart rate



For further information and how this is managed, please refer to:

https://longcovid.physio/dysautonomia-pots
https://www.potsuk.org/managingpots/

Returning to Work

Going back to work after fighting an infection can be challenging. The symptoms of Long Covid, such as fatigue, shortness of breath and poor concentration can make returning to work more difficult.

If you do not feel fit enough to return to work, the following steps may support your return and make it more achievable:

- 1. Talk to your GP
- 2. Consider contacting 'fit for work'
- 3. Obtain a fit note
- 4. Understand workplace modifications
- 5. Identify any support that would be helpful at work to you
- 6. Contact occupational health
- 7. Talk to your line manager

For more information on each point please refer to:

https://www.yourcovidrecovery.nhs.uk/your-road-to-recovery/returning-to-work/



Vaccinations

Immunisation strategies are one of the key elements to addressing the impacts of COVID-19 in the short and long term.

Vaccinations reduce the risk of reinfection which remains important for people with Long Covid, and evidence so far suggests that benefits are likely to outweigh any harms (8).

Vaccines reduce but do not eliminate the risk of Long Covid. Vaccines are very effective at preventing people from getting seriously ill from COVID-19 and avoiding infection is the surest way to prevent Long Covid (9).

Where to Find Help



HOPE programme for Long Covid:

https://www.h4c.org.uk/courses-all/2021/10/26/hope-programme-for-long-covid-tp3hd

Your COVID Recovery:

Your COVID Recovery | Supporting your recovery after COVID-19



COVID: Aid:



https://covidaidcharity.org/advice-and-information/long-covid-and-post-exertional-malaise

British Heart Foundation: <a href="https://www.blf.org.uk/support-for-you/long-covid?cmp_id=16446478055&adg_id=132331286605&kwd=long%20covid%20support&device=c&gclid=EAlalQobChMI_ry5pZvu9wIVSuvtCh3PUQzgEAAYAiAAEgKb5fD_BwE



Psychological therapies:

In each area of England there is an Increasing Access to Psychological Therapies (IAPT) service. These are services provided by the NHS. You do not need your doctor or a healthcare worker to refer you. You can get in touch and ask for an assessment. Also the websites have a lot of information.



The IAPT services in Devon and Cornwall are:

Cornwall – Outlook South West.

The website is https://www.cornwallft.nhs.uk/outlook-south-west - you can fill in a contact form or you can ring (01208) 871905.

Plymouth – Plymouth Options.

The website is: https://www.livewellsouthwest.co.uk/plymouth-options - where you can fill out a contact form or email plymouthoptions@nhs.net or ring 01752 435419.

Devon - Talkworks.

The website is: https://www.talkworks.dpt.nhs.uk/ - where you can fill out a contact form or you can ring 0300 555 3344.

All the services offer telephone and online appointments.

You can also speak to your GP.

National Support

A government website that can help you to access services and help from a wide variety of sources.

https://www.gov.uk/find-coronavirus-support



Plymouth Support Services

If you have been advised to continue self-isolating at home there are many local services that can help.

Caring for Plymouth: Support for the medically vulnerable. Specially trained staff will be ready and waiting to take calls on 01752 668000 between 8am and 6pm

Age UK Plymouth - Shop N Drop service, prescription collection service and weekly telephone call with a phone friend to keep you in regular contact with someone. enquiries@ageukplymouth.org.uk

Food Boxes Available: Age UK Plymouth with be taking orders for food boxes which will be available for delivery. Prices start from £10 per box. To place an order please call 01752 253980.

Other Plymouth support services:

Adult Social Services: 01752 668000 Improving Lives Plymouth: 01752 201890 Community Action Helpline: 07786683074 Extra Help: 01752 424515 Plymouth Labour Force: 07786683074



Devon Support Services

Devon: https://www.devon.gov.uk/coronavirus-advice-in-devon/document/community/#section-9

East Devon: District Council's Coronavirus Community Support Hub available to help local residents, communities and organisations access information and support.

Tel: 01395 571500, Monday to Friday 09.00-17.00.

Southwest Support Services

Coronavirus community assistance directory: help in your community https://coronavirus.scvo.org/

Age UK Tel: 08006781602, lines open 08.00-19.00 every day.

University Hospitals Plymouth NHS Trust

References

- Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK Office for National Statistics (ons.gov.uk)
- 2. https://wiltshirehealthandcare.nhs.uk/service/bsw-long-covid-rehabilitation-assessment-clinic/
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- 4. https://www.nia.nih.gov/health/cognitive-health-and-older-adults
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 - fog/#:~:text=Symptoms%20may%20vary%20and%20change,affecting%20how%20your%20brain%20fu nctions.
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- 7. https://www.bda.uk.com/resource/long-covid-and-diet.html
- 8. https://www.bmj.com/content/377/bmj.o988#:~:text=Vaccination%20to%20reduce%20risk%20of,likely%20to%20outweigh%20any%20harms.
- 9. https://www.nytimes.com/article/long-covid-vaccines.html

This information booklet is available in large print and other formats and languages. Please contact:

Patient Services

Tel: 01752 763 031

This book has been written by the COVID Respiratory Rehab and Discharge Team at Derriford Hospital. With many thanks to all colleagues and patients for their help.

Please follow the link below or the QR code for videos created by our own COVID red team here at Derriford Hospital. These videos are designed to guide you, further your knowledge and start your rehabilitation to your road to recovery.

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