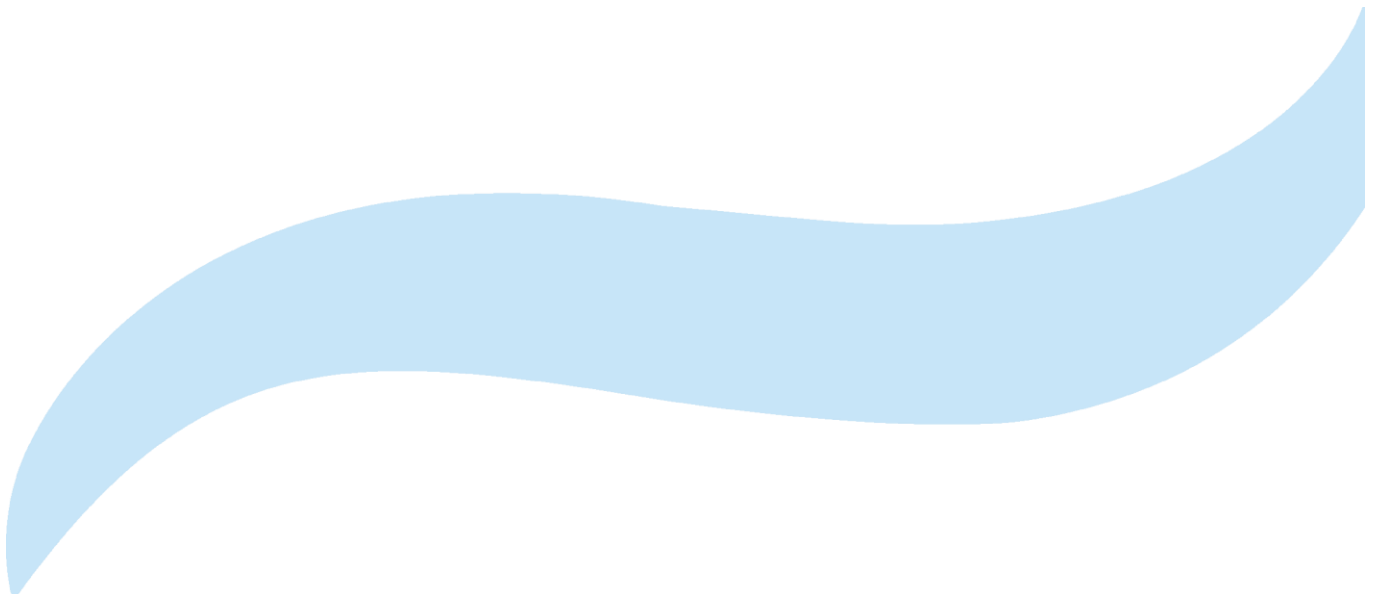


Long Covid Workbook

Early Support & Symptom Management

Name: _____



Introduction

Long Covid affects people in different ways. There are a lot of different symptoms of Long Covid and these can vary between different people. In some people, symptoms can be mild and get better quickly. However, for others, Long Covid symptoms can be difficult to manage, last a long time and be life changing. Each experience is different, and it is important to tailor your self management to your own symptoms, and what you will find helpful.

This workbook will give you information on techniques to self manage the most well-known and most common Long Covid symptoms. Self management is about taking action and helping put you in the driving seat of your support. This workbook will support you to develop new skills to help manage your symptoms, find information about a variety of issues experienced when living with Long Covid, and find the support which best suits you.

Whilst trying out the skills and recommendations in this workbook, keep your health professionals updated with what is working for you, and which areas you need more support in. Give yourself enough time to try the skills, but make sure to listen to your body and stop if you have a negative response to any new techniques.

Please complete the parts of the workbook that are related to your symptoms: You **do not** need to read or complete the whole workbook. The workbook covers a lot of information, and not everything will be relevant to you – use the contents page to navigate through the workbook.

Long Covid symptoms can also interact with other conditions you might have, such as respiratory conditions or diabetes. If you experience this, contact your GP or healthcare professional. Speak to your GP, or any other healthcare professional, if you develop symptoms not included in this workbook, or if your symptoms become worse.

If you are still struggling with your Long Covid symptoms after trying the recommendations in this workbook for a period of time which works for you, contact your GP or health professional for further support. If you experience sudden shortness of breath, or your breathlessness gets worse suddenly, for no apparent reason, please call 111.

What is Self Management?

Self Management is about people living with long term conditions being in 'the driving seat'. This means thinking about what matters to you and having support to help you to live your life better, on your terms. Self management is **never** about being left to manage your condition on your own, it is about enabling people to live their lives on their terms. Self management always involves healthcare professionals, and if you need further support with your self management, please contact your GP.

Self Management can mean people being:

- better informed about their condition(s)
- better prepared for everyday challenges
- better supported when they need it

This workbook will help you to develop the tools you need to self manage your Long Covid symptoms, and to get you started on your self management journey.

Who Is This Workbook For?

This workbook is for you if:

- ❖ You are 16 or older.
- ❖ You still have symptoms 12 weeks after having Covid-19. You do not need to have a positive Covid-19 test.
- ❖ If your doctor told you that your symptoms are related to Long Covid.
- ❖ If your GP or the healthcare professional told you to read and use this workbook.

The focus is on managing symptoms to be able live your life to its full potential. This workbook can act as a guide for self managing symptoms.

For resources specifically for children and young people, we recommend visiting Long Covid Kids.

You can find them at <https://www.longcovidkids.org/>

How do I work my way through this workbook?

1. Write down the difficulties you are struggling with.
- 2. Read the sections related to your difficulties.**
3. Take notes of the strategies you would like to help you plan how you will manage your symptoms. Write them down in the toolbox section at the end of this workbook, (page 75).
4. Complete the 'Looking Back', (page 76) section.
5. Think about what is important to you. What symptom are you struggling the most? In what areas would you like your life to be better?
6. Complete the 'My Goals', (page 78) section.
7. Practice the strategies that you learned.
8. Look back to your toolbox section for help when you are struggling.

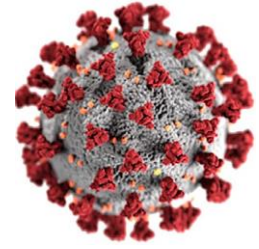
The next page tells you the different sections of the workbook and their page number. Tick the box next to the sections you want to read.

Contents

Introduction.....	2
Who Is This Workbook For?.....	3
What Is Coronavirus?	5
What Is Long Covid?	6
Managing Fatigue	7
Post Exertional Response (PESE and PEM)	16
Activity.....	21
Managing Breathing Difficulties	27
How To Help Your Cough?	34
Managing Voice Problems.....	36
Nutrition	37
Managing Swallowing Difficulties.....	39
Change Or Loss Of Smell And Taste	40
Covid-19 And Emotions.....	42
Postural Orthostatic Tachycardia Syndrome (POTS) And Other Forms Of Dysautonomia	55
Dizziness.....	58
Managing Sleeping Difficulties	59
Managing Pain	64
Brain Fog.....	65
Work And Education	66
What’s Next?	74
Resources	79

What Is Coronavirus?

Coronaviruses are a large family of viruses. Covid-19 is known as Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2). This specific type of coronavirus is more serious than others in the group.



Covid-19 can spread by aerosol or droplet particles from the nose or mouth. This means that if you have Covid-19, you can spread it if you cough, sneeze or breathe close to others.

Common symptoms of Covid-19 (some of which you might have had when you first got Covid-19) are:

- ❖ a dry cough that doesn't go away
- ❖ high temperature
- ❖ loss or change in your sense of smell or taste
- ❖ headache
- ❖ feeling very tired
- ❖ sore throat
- ❖ blocked/runny nose
- ❖ stomach pain and diarrhoea
- ❖ feeling breathless
- ❖ confusion

Symptoms usually last between 7-14 days. Most people will fully recover from Covid-19 within 2-6 weeks.

What Is Long Covid?

Long Covid is the term used to describe people who have symptoms for over 12 weeks after having a Covid-19 infection. Your likelihood of having Long Covid is not affected by how severe your initial Covid-19 infection was. If your symptoms continue for more than 12 weeks, contact your GP.

The most common Long Covid symptoms are:

- ❖ Feeling very tired (fatigue)
- ❖ Poor concentration
- ❖ Feeling short of breath
- ❖ Muscle ache

Other common symptoms are:

- ❖ Getting very tired after an activity
- ❖ Problems with your voice
- ❖ Low mood
- ❖ Stress and anxiety
- ❖ Problems with remembering things

But there have been over 200 symptoms described as being part of Long Covid.

If you have any of these Long Covid symptoms, then this workbook is for you. It will help you develop new skills to manage your symptoms on your own.

Long Covid symptoms will be different for each one of us. Not everyone will experience them in the same way. This workbook can't cure your symptoms but can help you to manage them better in order to go back to a more independent, happy life.



Long Covid is also known as:

- 'chronic Covid'
- 'post Covid syndrome'
- 'Post-Acute Sequelae of SARS-CoV-2 infection'
- 'Post-Acute COVID-19'

You can find out more about Long Covid at NHS Inform:

<https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid>

Managing Fatigue

What is Fatigue?

It is extreme tiredness that does not go away with sleep or rest. This lack of energy can make your arms and legs feel heavy, and it can make you feel grumpy and emotional. It can reduce your concentration and motivation, so you may struggle to carry out day to day tasks. Fatigue is one of the most common symptoms of Long Covid and may stop you from getting back to work, cooking a meal, looking after someone, talking to a friend, or going shopping.

The amount of fatigue you have may change from day to day (or hour to hour), and certain activities may make it worse. An increase in your level of fatigue can last for several hours (or days) and may be slow to improve.

When you are experiencing fatigue, make sure to rest on both your good and bad days. It is important to listen to your body, and rest when you need it, even if you don't feel tired yet.

Some of the most common features of fatigue are:

- ❖ Struggling to carry out every day activities
- ❖ Feeling of heaviness in the body
- ❖ Lack of concentration
- ❖ Brain fog
- ❖ Changes in eating habit
- ❖ Not coping with noise, smell, or bright light
- ❖ Feeling grumpy
- ❖ Finding it difficult to chat
- ❖ Feeling 'off balance'
- ❖ Whole body tiredness
- ❖ Having no energy
- ❖ Pain
- ❖ Feeling unable to cope
- ❖ Difficulty solving problems
- ❖ Struggling to make decisions
- ❖ Feeling emotional
- ❖ Problems sleeping

Causes of fatigue can be physical, mental, emotional and environmental (your surroundings). Understanding what makes you fatigued can help you take steps to make it better. In this part of the workbook, we will look at how fatigue affects your life, and give you tools to help you manage it.

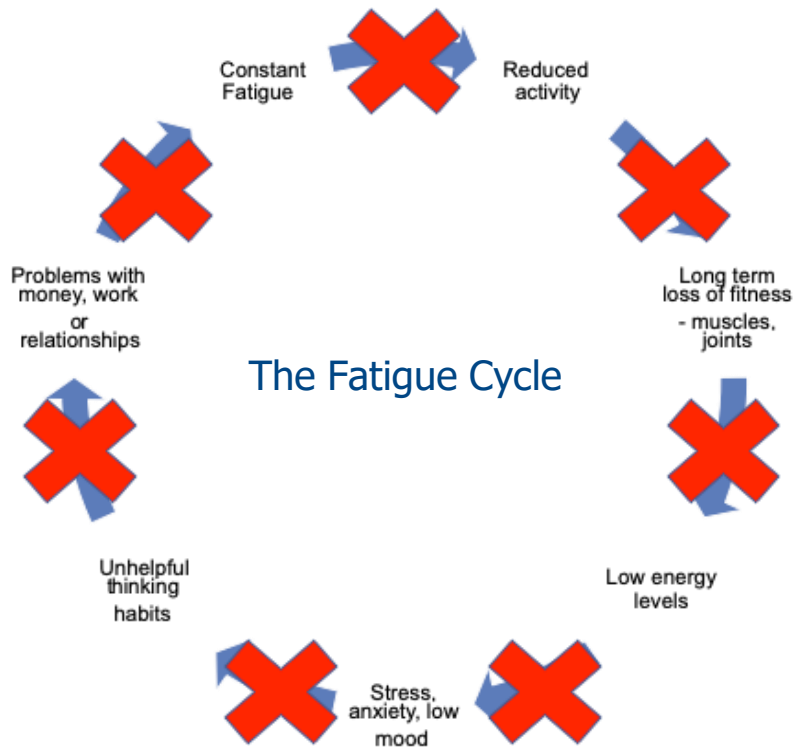
Boom and Bust

If you have fatigue, you may feel that you are going round and round in circles. You may try to do as much as possible when you have some energy, and then feel much worse after because you have done too much. When you feel worse you need lots of rest to help you recover.

This is called Boom and Bust.



Are you in a Boom Bust cycle? Is fatigue taking over your whole life? Let's look at how you can break this cycle to help gain control over your day to day activity.



Fatigue and Energy Levels

We all have our own battery to give us energy during the day. When we run out of energy, we need to recharge our battery. When you are fatigued, it can take longer than 'normal' to recharge your battery. That is why it is important to keep track of our energy/battery levels.

Think about how much energy you need to carry out each daily task. You can do this by working out how you feel and what you can do when you have different energy levels. Start by filling in the following statements:



When my battery is fully charged, I feel ... _____



When my battery is half charged, I feel ... _____



When my battery is empty, I feel ... _____



When my battery is empty, I can do ... _____



It is important to sleep, rest, eat and drink enough to help recharge your batteries and allow your energy to recover. Now that you know how you feel when your battery is full, half full and empty, let's look at how you can manage your fatigue by pacing your activity.

PACING YOUR ACTIVITIES

Pacing is a way of increasing your activity levels without making your fatigue worse. It involves balancing activity with rest to make sure your battery never runs out of charge. Pacing is one of 'the 5 Ps' that can help you break out of the Boom and Bust cycle and build your energy levels.

The 5 Ps are:

- ❖ Prioritising the most important tasks in your day
- ❖ Planning how you will carry out these tasks
- ❖ Pacing to break daily tasks down into smaller parts
- ❖ Position yourself correctly
- ❖ Permission to say NO or ask for help

Prioritise

Ask yourself the following questions to find out which of your daily activities are important for today:

- ❖ What do I NEED to do today?
- ❖ What do I WANT to do today?
- ❖ What can wait until another day?
- ❖ What can I ask someone else to do for me?



Think about which activities are most important to you each day and make those activities your priority.

Plan

Planning what you need to do on a daily or a weekly basis can help you to organise your activities and build in time to recharge your batteries.

It is helpful to plan all the tasks you need to do in each room ahead of time. This cuts down the amount of walking and energy needed. Try to do all the tasks in one room before moving to the next. Take your time and have breaks when you need them.

Which times of day are best for you to be active or at rest? Do you have more energy in the morning or at night? Try not to do too much in one day, with tasks balanced with rest. For example, food shopping, laundry, and changing the bed, can be done on different days with rest days in between.

Top tips for planning your day:

- ❖ Collect all the items you need before you start a task
- ❖ Sit to carry out a task if possible
- ❖ Take regular breaks
- ❖ Do one thing at a time – try not to multi-task
- ❖ Ask for help from friends or family where you can
- ❖ Use delivery services to bring items to you – for example using online shopping



Pace

It is important to balance activity with rest. You may need to rest during activity and allow yourself some extra time to finish what you are doing. Pacing will help you have enough energy to manage your daily activities. It will help you recover faster if you work on a task until your battery is half full rather than empty. Slow and steady wins the race!

Finding a healthy balance can be quite difficult, as on some days you will have more energy than others. Make sure to rest on both 'good' and 'bad' days, and rest before you feel fatigued.

Top tips for pacing yourself during the day:

- ❖ Break up activities into smaller tasks
- ❖ Use the phone or internet rather than going out
- ❖ Spread tasks throughout the day
- ❖ Build in regular rest periods
- ❖ Plan to rest and recharge between activities
- ❖ Set an alarm (on your phone) to remind you to stop and rest
- ❖ Sit and rest when you can

Position

Having good postures and comfortable body positions when carrying out tasks (including resting) is really important to help you save energy. For example, sitting in a supportive armchair when watching TV or leaning your hips against the kitchen worktop when washing the dishes.

Good posture lowers the amount of energy needed, as muscles don't need to work as hard. If possible avoid stretching, over-reaching and bending down. Think about how you sit and stand during the day - can you change your posture or position to stop you getting uncomfortable?

Top tips to improve your posture during the day:

- ❖ Get closer to a task to avoid over-stretching
- ❖ Use both hands when lifting and carrying
- ❖ Keep frequently used items close together (tea and coffee near the kettle)
- ❖ Slide items along work surfaces
- ❖ Sit down to do tasks if you can (peeling potatoes over a bowl on the table, or sitting on the toilet when brushing your teeth)
- ❖ Use gravity to help you – allow something to fall rather than place it on the floor

Permission

Allow yourself NOT to do tasks that make you breathless and fatigued. It is OK to say NO, and also OK to ask for help from family or a friend when you are finding things tough.

Show them your activity diary so they get an idea of what you can manage. Tell them what you need help with.

Instead of thinking 'I must' or 'I should', try to change your thinking to 'I choose to', 'I would like to' or 'I wish to'. Don't force yourself to do too much and stop and rest if you are getting too puffed out or tired.



ENERGY CONSERVATION

How many times have you put your mobile phone onto power saving mode because you want it to last a bit longer? Your phone is saving the battery from running out of charge, and this is what you need to do too. The next part of the Workbook shows you how to save your own battery to cope with fatigue and tiredness by using your energy in the best way.

Washing & grooming

- ❖ Sit to brush your teeth and dry your hair.
- ❖ Avoid aerosols (spray cans) and strong scents.
- ❖ Wash hair in the shower, keep elbows low and chin tucked in.
- ❖ Support elbows on counter when grooming.
- ❖ Do not hold your breath when shaving.
- ❖ Use an electric toothbrush and shaver.

Bathing and showering

- ❖ Wash at a time when you have enough energy.
- ❖ Allow plenty of time.
- ❖ Gather everything you will need, including clothes.
- ❖ Keep items within reach.
- ❖ Use a stool or chair in your shower.
- ❖ Sit to undress, wash, dry and dress.
- ❖ Use a long handled sponge to wash back and feet.
- ❖ Decrease steam by turning cold water on first and slowly adding hot water.
- ❖ If oxygen is prescribed for exercise, use it when showering.
- ❖ Open the bathroom window to allow steam to escape.
- ❖ Use a towelling bathrobe to dry your body.



Dressing

- ❖ Before starting, gather all clothes together.
- ❖ Keep control of your breathing. Breathe out with effort.
- ❖ Sit down to get dressed.
- ❖ Dress the lower half of your body first.
- ❖ Cut down on bending by crossing one leg over the other when putting on socks and shoes.
- ❖ Long handled tools can help you put on socks, pants and shoes.
- ❖ Pull up pants and trousers at the same time in one stand.
- ❖ Slip-on shoes, velcro straps or elastic laces may help.
- ❖ Dress the upper body last with buttons and zips on the front of clothes.

Cooking

- ❖ Cook larger amounts and freeze some.
- ❖ Prepare part of the meal ahead of time.
- ❖ Use recipes that need little time and effort.
- ❖ Gather all items before beginning.
- ❖ Sit if possible (to cut up food and wash dishes).
- ❖ Make one pot meals.
- ❖ Use pre-prepared fresh or frozen products.
- ❖ Serve food from the baking dish.
- ❖ Use electric tin openers and other powered kitchen tools.



After meal clean up

- ❖ Rest after your meals before starting to clean up.
- ❖ Have everyone clear their own place setting.
- ❖ Use a trolley to transport items instead of carrying.
- ❖ Your washing up bowl should be at a comfortable height.
- ❖ Wash dishes in a circular motion.
- ❖ Let dishes soak so you don't need to scrub them.
- ❖ Let dishes air dry.
- ❖ Use a dishwasher if you have one.
- ❖ Use rubbish disposal, empty bins frequently or have a family member do it.



Shopping and meal planning

- ❖ Order online if possible.
- ❖ Organise your shopping list to match the layout of the supermarket.
- ❖ Shop when the store is quiet.
- ❖ Get help reaching for items and for carrying heavy bags.
- ❖ Ask the shop assistant to pack your shopping lightly.
- ❖ Make a few trips to bring your shopping into the house.
- ❖ Take the cold and frozen food first, and get the other items later after a rest.

Housework

- ❖ Spread out chores over the whole week.
- ❖ Clean a different room each day.
- ❖ Sit down to dust and use a long handled duster.
- ❖ Use a light weight hoover if possible.
- ❖ Use long handled cleaning attachments on the hoover.
- ❖ Use a mop to clean up spills instead of bending down.



ENERGY DIARY

An energy diary helps you to work out how much energy you are using during your daily activities. It will also help you see what activities are bringing on (or triggering) your symptoms.

It is also useful to help you work out what kind of energy you are using during each activity. Activities may use one or more of the following types of energy: physical, mental, emotional, sensory or social effort.

Once you are able to identify your triggers, you can use this diary to help you balance your energy levels. Planning your day to include rest periods can help improve your symptoms and manage your energy.

How to use an energy diary:

- ❖ Look back at page 8 to see how you feel and what you can do when your batteries are fully charged, half full and nearly empty.
- ❖ Think about what activities you NEED to do and what you WANT to do.
- ❖ Prioritise, Plan and Pace your day.
- ❖ Make sure you have good posture during tasks.
- ❖ Allow yourself to say NO to tasks.
- ❖ Spread rest and activity evenly throughout your day.
- ❖ Include activities that you enjoy and are fun to do.
- ❖ Break activities down into chunks.
- ❖ Try to do fewer physical activities in the evening.

ENERGY DIARY

ENERGY DIARY																								
Week	Morning - a.m.													Afternoon / Evening - p.m.										
/ /	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

The key shows you what colours to use for each level of activity

	High Energy Activity		Low Energy Activity		Rest/Relaxation		Sleep	/	Crashed
--	----------------------	--	---------------------	--	-----------------	--	-------	---	---------

Post Exertional Response (PESE and PEM)

It is common for your symptoms to get worse after you do something that uses energy.

Your symptoms getting worse after you use energy on something (also called exertion) is called **Post Exertional Symptom Exacerbation, PESE**. For some people this can mean that their 'normal' symptoms become worse. In other more severe cases, it can feel like you have Covid-19 again. These symptoms can really affect how you are able to recover from Covid.

It is also often called **Post Exertional Malaise, PEM**, but technically this only refers to the symptom of fatigue

We will help make you aware of how to recognise it and give you advice on how to manage this. For many PESE causes the tricky problem of 'to exercise or not to exercise'.

The following two questions may help you find out if you experience PESE:

1. Do you experience severe fatigue (extreme tiredness), with at least 3 symptoms in the categories below?
 - a) feel unwell
 - b) feel weak
 - c) don't sleep well
 - d) have pain
2. Does it take a day or more to recover if you have had to use a lot of energy?

If the answer to both questions is **yes**, then you may have PESE



Symptoms often worsen 12 to 48 hours after activity

it can last for days, weeks or even months

- sleep disturbance
- fatigue and exhaustion
- pain
- 'Brain Fog'
- Heart palpitations
- Fever/ high temperature

When people with fatigue do too much, or use up all their available energy supplies, they stop being able to carry out activities. This is not improved with a long rest or a good sleep. For some people, this means that they are unable to work or carry out household tasks without making their symptoms worse. In some severe cases, the things that our bodies normally do such as: digestion, heartbeat and breathing, can make symptoms worse.

Post-exertional symptom exacerbation (PESE)

Is a symptom that can be very disruptive and often described as a 'crash'. The activity that triggers this to start off does not need to be a *hard* or *big* activity.

It can be something that was previously normal to you, like:

- socialising
- Reading, writing or working
- An emotionally heavy conversation
- Daily activity ; showering, doing the dishes
- Sensory environments (loud music or bright lights)
- Walking or other exercise



People with fatigue and PESE are thought to have a change in the way their energy is made. So, the normal way that we produce energy through using oxygen is reduced (aerobic fitness), and the body tries to produce energy in another way instead (this is called anaerobic fitness). This is not as fast at giving you energy, so you will get tired quicker. It takes much longer for your energy levels to recover if you have fatigue, so your symptoms might last longer.

How do I deal with it if it happens?

Finding your comfort zone:

Your baseline is what your 'normal' is – this is not your pre Covid-19 infection normal. It is when your body has no symptoms and feels 'normal'. There are things that you can do to help you find your baseline.

Activity diary

An activity diary helps you to record what activities you have carried out over the space of a week. It looks at how breathless you felt while you were doing these activities, and the fatigue you felt afterward.

You may not have to get breathless to bring on PESE. Things like loud, bright environments or very emotional conversations might bring it on, rather than physical activity.

STOP
Pushing yourself past your limits. Listen to your body!

REST
Is the most important way to manage your symptoms.

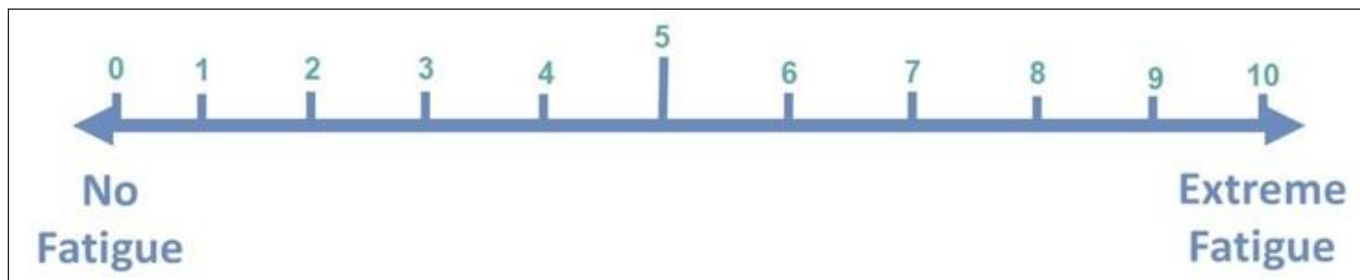
PACE
Take time to complete activities and do not try to do everything.

Day	6 - 9am			9 - 12am			12 - 3pm			3 - 6pm			6pm - bedtime		
	Activity	Fatigue	Borg	Activity	Fatigue	Borg	Activity	Fatigue	Borg	Activity	Fatigue	Borg	Activity	Fatigue	Borg
Monday															
Tuesday															
Wednesday															
Thursday															
Friday															
Saturday															
Sunday															

How to use the activity diary?

- ❖ Keep a note of the activities and rest periods that you have taken during each time period. Mark this in the column that says 'Activity'.
- ❖ Score your fatigue or worsening of symptoms at the end of each time period using the first scale below. Put this in the column that says 'Fatigue'.
- ❖ Score how hard you find the activity using the second scale, The Borg Scale below. Put this in the column that says 'Borg'

Fatigue Scale



Borg Scale

6	No exertion	
7		
8	Very light	
9		
10		Breathing a bit deeper, but still comfortable
11	Light	
12		Breathing harder, but still able to hold a conversation
13	Somewhat hard	
14		
15	Hard	Starting to breathe hard and uncomfortable
16		
17	Very Hard	
18		
19		Extremely hard
20	Maximal exertion	

This will let you see what activities are contributing to your PESE, and it may help you to find out what things are triggering it (bringing it on).

If you can find triggers, and either cut them out completely, or reduce them to a manageable level, this should help to improve your symptoms and energy levels.

Build in rest periods

The level of activity/rest that you can manage without making your symptoms worse is known as your baseline activity. Finding this will take time, but it will let you gradually manage to do a little bit more of the activities you managed to do before you had Covid-19.

Please also see the sections on pacing.

Self-monitoring activity

The Workwell Foundation advises that if you have PESE, you should have a maximum heart rate of 15 beats per minute above your normal resting heart rate, when you are doing any activity.

This means that if your heart rate climbs to 15 beats higher than your resting heart rate, you should stop the activity to prevent PESE. A heart rate monitor may help you to keep an eye on this at home.

This is because above this rate your body naturally starts to use the method of creating energy without oxygen. This means that your energy will run out faster.

How to calculate resting heart rate:

- ❖ Rest for 10 minutes
- ❖ Feel your pulse at the thumb side your wrist with 2 fingers
- ❖ Count the number of beats for 30 seconds
- ❖ Multiply this by 2 to get the number of beats per minute

Pedometers/ Step counters

Using something to count your steps, such as a smart watch or your phone, can help you see how active you have been. This is very helpful if physical activity is a trigger for your PESE. It may also help you find out how much of an activity you can do without making your symptoms worse. This can help you with pacing (see the Activity section on page 21).

Resting

Resting your body, mind and senses will allow you to recover quicker. Resting will differ between people, depending on what triggers their PESE. This may involve lying in a quiet dimly lit room; it could be guided relaxation, mindfulness, or breathing work.

Some people might find watching television or listening to music as restful, but if you have sensory triggers, these activities will make your symptoms worse.

It can be difficult to rest if you feel bored, if there is pressure on you to get back to doing your 'normal' activities, if you want to use the energy which you have got back after resting, or if you want to distract yourself from the symptoms you are having when you are resting.

Therefore, rest takes practice and willpower.

Some people may have a combination of lower tolerance for exercise, be weaker, and have PESE. People with PESE must deal with PESE first before thinking about dealing with the other two.

By keeping a close eye on how your body copes with an activity, you can use your symptoms to help you manage things.

If you have reduced exercise tolerance, or if you are weaker, but you do not have PESE, it is safe for you to gradually increase the amount of activity you are doing.

'No pain, no gain' does not apply here and can be damaging to your recovery

Activity

This section of the workbook will look at activity and Long Covid and will recommend various tools which can be used to assess how much activity and exercise you can handle and gives examples of exercises to get you started. This is often called 'pacing'.

Pacing can be difficult. Learning to recognise how much energy you have, where your limits are, and if you can push these limits, can be confusing. Gentle activity is a good place to start, and you can increase your activity in line with how your body feels and set realistic goals. These goals can be large or small and should be manageable for you.

An example of this is walking to visit your neighbour, sitting in the garden, or following an at-home yoga tutorial online. Whilst some of these examples will be achievable for some people living with Long Covid, they will not be for others. Make sure to tailor your activity to your own capabilities.

Before you exercise, you must make sure that you are safe to exercise. If you are not sure, speak to your GP or another healthcare professional.

Make sure that you are resting before you reach your limit, and make time to rest every day, not only on your 'bad days'.

What is exercise tolerance?

Exercise tolerance is how much you can exercise before you have to stop. This will help you manage your daily activities. The things that will make you stop are: feeling breathless, fatigue (extreme tiredness) and/or pain. We want you to stop **before** you are feeling breathless or fatigued. Poor exercise tolerance will happen if you have not been moving about for a long time or if you have been unwell. This means that you are not able to do as much as you used to be able to.

Problems with your heart, lungs, nerves, bones or muscles can stop you from being able to exercise. This can make you feel breathless when you are walking, or going up and down stairs. You may also be weaker than you were before and feel more tired during or after activity.

Safe rehabilitation can make you fitter and stronger.

A good way to start exercising is a walking (or stepping) program. The starting level will vary between people. Things that can make you less fit are:

- ❖ Older age
- ❖ Other illnesses
- ❖ Obesity
- ❖ Bad diet
- ❖ Long Covid symptoms
- ❖ Smoking

Start low and go slow

This chart on your right shows the Borg Scale which helps to measure how short of breath you are.

You should aim to be in the 'green', between 11 and 13, when undertaking activity.

You must start at a safe level for you

Other people may find that they can manage to walk for 5 minutes. For example:

- ❖ Walking 5 minutes twice a day on Day 1
- ❖ Increase this very cautiously when you feel comfortable to do so (have been consistently in the 'green')

Some people will find that marching on the spot for 1 minute may be enough to start with. For example:

- ❖ Marching on the spot for 1 minute several times on Day 1
- ❖ Increase this very cautiously when you feel comfortable to do so (have been consistently in the 'green')

There may be some people who need to be more careful when making exercise harder. For example, you may need to increase your workout time every 3 - 4 days, instead of every day. It is important that you do what is safe for you and if you don't know, speak to a healthcare professional able to help you.

6	No exertion	
7		
8	Very light	
9		
10		Breathing a bit deeper, but still comfortable
11	Light	
12		Breathing harder, but still able to hold a conversation
13	Somewhat hard	
14		
15	Hard	Starting to breathe hard and uncomfortable
16		
17	Very Hard	
18		
19		Extremely hard
20	Maximal exertion	

Remember:

- ❖ Building up activity levels is not straightforward.
- ❖ Keep going back to what feels right for you and use the Borg scale to help.
- ❖ It can vary from day-to-day.
- ❖ Listen to your body and adjust accordingly.

What is deconditioning?

Decrease in muscle mass will make you weaker. It is harder to do your daily activities like housework, preparing meals and exercise. This means you are deconditioned. If you are deconditioned, you will have to work harder when you are doing activities, you may tire more quickly, and you may be more breathless.

What causes deconditioning?

- ❖ Long stay in a hospital
- ❖ Having long-term problems like Long Covid
- ❖ Injuries like broken bones or back pain
- ❖ Bad eating habits
- ❖ Obesity
- ❖ Older age

Examples of strengthening exercises

Once you are managing everyday activities, you may feel ready to start exercising. Here are some exercises for you to try.

Increase your activity and exercise levels gradually. If you get tired, stop and rest, then start again once you feel better.

No exercise should be painful. If you experience pain, chest pain, or feel faint or dizzy during exercise you should **stop** immediately and not restart your exercise programme until you have seen a healthcare professional.

How often should I do the exercises?

Short, regular bouts of exercise may be easier for you.

- ❖ Repeat each exercise five times
- ❖ If this is too difficult, do three.
- ❖ If it is too easy add two or more!

If any exercise causes you a problem, STOP.

EXERCISES IN LYING – STAGE 1

Lie on your back for all these exercises in a comfortable position such as on your bed, sofa etc. Repeat both sides.

1. Ankle Movements

With your legs straight, bend and straighten your ankles with your toes pointing away/back.



2. Buttocks Squeeze

Squeeze your buttocks together and hold for a fixed period, for example 10 seconds, then relax.



3. Arm Reach

Lift your arm up slowly and controlled up towards the ceiling then return it back down to your starting position.



4. Leg Lifts

With one leg straight and the other bent with your foot on the bed.

Squeeze the muscles of your straight leg and lift it up off the floor keeping it straight. With control lower it back down to the starting position.

It does not have to go very high. Even a small lift is effective!



5. Leg Slides

Slide your leg gently out to the side then return back to starting position.



EXERCISES IN SITTING – STAGE 2

1. Shoulder Circles

- Roll your shoulders forward in a circle.
- Roll them backwards in a circle.



3. Arm raises to the side

Hold a light weight, start with your hands by your side, lift away from your side up to shoulder level. If too difficult, perform with no weight.



5. Mini Knee lifts

Sit up straight in your chair, feet flat on the floor and place your hands on your knees. Lift one foot off the floor then slowly replace it. Repeat with the other foot. This will work your back and tummy muscles.



2. Bicep Curls

Hold a small bottle of water or similar comfortable weight. Gently bend your elbow, moving your hand towards your shoulder and lower again. Repeat with other arm.



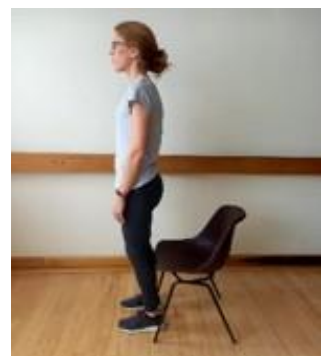
4. Leg Extensions

Slowly straighten your knee, hold for a count of three and relax. Repeat with other leg.



6. Sit to stand

Begin sitting towards the edge of your chair and lean forward: Stand up slowly then sit back down carefully. Keep your feet on the floor at all times.



EXERCISES IN STANDING – STAGE 3

1. Wall push off

- Place your hands flat against a wall at shoulder height.
- Fingers facing up.
- Feet shoulder width apart, around 30 cm away from the wall.
- Slowly lower your body towards the wall by bending your elbows, then gently push away from the wall again, until your arms are almost straight.



2. Squats

- Stand with your back against a wall or other stable surface and your feet slightly apart and about 30 cm away from the wall.
- Keep your back against the wall or holding on to a chair.
- Slowly bend your knees.
- Keep your hips higher than your knees.
- Pause for a moment before slowly straightening your knees again.



3. Heel raises

- Rest your hands on a stable surface (such as chair) to support your balance, but do not lean on them.
- Slowly rise on your toes and slowly lower back down again.



5. March on the spot

- Stand with or without support.
- Raise one knee up then the other and repeat for a comfortable period, for example 10 seconds.



4. Leg to side

- Stand straight holding on to a support if you need to.
- Lift your leg sideways and bring it back, keeping your body straight throughout the exercise.
- Repeat with other leg.



Managing Breathing Difficulties

WHY DO I FEEL BREATHLESS?

It is common for people who have had Covid-19 to feel breathless. Some of your breathing difficulties may not have got better yet. You may be taking quicker, shorter and shallower breaths. You may notice that your shoulders are raised as you tense up and try and take in more air. Breathlessness can also be made worse by anxiety.

If you feel anxious and worried about being breathless this can make your muscles tense and cause your heart to beat faster. This can then make you breathe faster and make your breathlessness and anxiety worse. That is why it is important to stay in control of your breathing.

Some of the reasons why you still feel breathless are:

- ❖ You may be producing too much mucus (fluid that coats and protects the inside of your airways).
- ❖ You may have a chesty cough.
- ❖ You may be less fit than you used to be because you're not moving about and exercising as much.
- ❖ Covid-19 may have caused some damage to your lungs.
- ❖ Your blood is pooling in the lower part of your body making you feel short of breath when you stand up.
- ❖ You have residual inflammation in your lungs and/or blood vessels.
- ❖ You may be anxious.

If your breathlessness gets worse suddenly, for no apparent reason, you should speak to your GP or call 111

Let's take a moment and have a think about what normal breathing should look like.

Normal breathing should be something you do without even thinking about it, it should be easy to do and you should breathe in through your nose. When we breathe in this way the air is filtered to remove any bacteria and dust. It's warmed up so it's the right temperature for your lungs and it becomes wet in your nose. Normal breathing should be quiet. Your breath out should be slightly longer than your breath in.

The diaphragm is the main muscle that controls your breathing. When we breathe in, the diaphragm pulls your ribcage down, sucking air into your lungs. When you breathe out, the diaphragm relaxes and you let go of the air. Breathing out should require no effort whatsoever. When you don't breathe like this you use up more energy and can get tired easily.

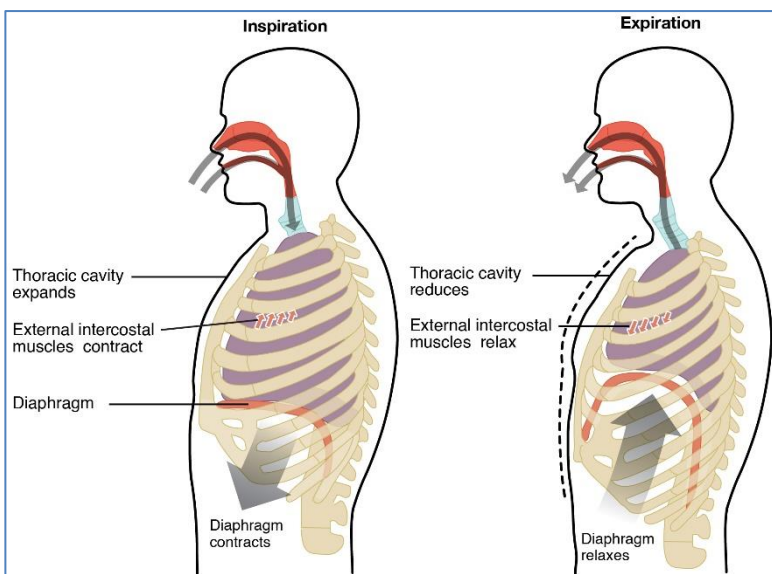


Image Credit: [OpenStax College](#)



TAKE A MOMENT NOW TO PAY ATTENTION TO HOW YOU BREATHE

Place one hand on your stomach and one on your chest. Now ask yourself the following questions:

- ❖ Does your chest move a lot when you are breathing?
- ❖ Can you hear yourself breathe?
- ❖ Do you breathe through your mouth?
- ❖ Do you notice yourself sighing, yawning, taking deep breaths, sniffing or coughing?

If you answered yes to any of these questions, you are using up a lot of energy when you breathe in and out. This is known as a breathing pattern disorder.

Please don't worry, having a breathing pattern disorder is a common thing. Over the next few pages we will give you hints and tips to help you learn how to breathe better.

BREATHING RETRAINING

Practicing good breathing is not easy. Thinking about breathing well and practicing regularly will help you see improvements.

Pain and stiffness in your neck and back makes it harder for you to breathe well. The following exercises will help stretch your back, neck and shoulders and help you to breathe better.

CHAIR BASED STRETCH

1. Sit on the chair with your feet flat on the floor.
2. Keeping your feet in place, turn your body to the right.
3. Place your right arm towards the back of the chair.
4. With your left hand, hold the arm of the chair.
5. Gently turn your body towards the back of the chair - You should feel a stretch in your spine.
6. Hold this position for a comfortable period, for example 10 seconds.
7. Relax and return to the start position.
8. Repeat on the other side, turning your body to the left.
9. If able, do these 2 more times on each side.



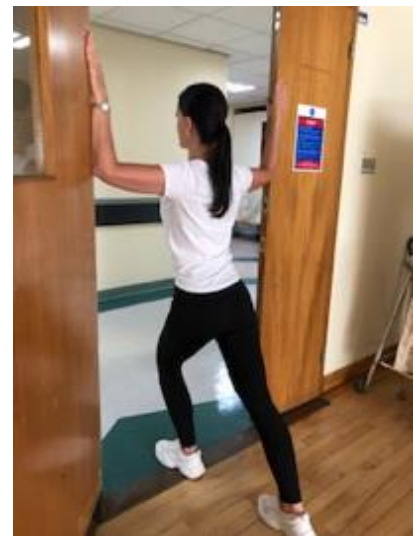
NECK STRETCH

1. Sit on the edge of a chair or your bed.
2. Place your feet flat on the floor.
3. Reach your right arm behind you to give you support.
4. Sit up tall and look straight ahead.
5. Place your left hand on top of your head.
6. Gently pull your left ear to your left shoulder.
7. You will feel a stretch in your neck and right shoulder.
8. Hold this position for a comfortable period, for example 10 seconds.
9. Relax and return to the start position.
10. Repeat on the other side, putting your left arm behind you.
11. Do these 2 more times on each side.



CHEST STRETCH 1

1. Stand in an open doorway.
2. Raise your arms up to the side, bent at 90-degrees with palms facing forward.
3. Rest your palms on the door frame.
4. Stand up tall and don't lean forward.
5. Slowly step forward with your left foot.
6. You will feel a stretch in your shoulders and chest.
7. Hold this position for a comfortable period, for example 10 seconds.
8. Step back and relax.



CHEST STRETCH 2

1. Stand in an open doorway.
2. Raise your arms above your head with palms facing forward.
3. Rest your palms on the door frame.
4. Stand up tall and don't lean forward.
5. Slowly step forward with your left foot.
6. You will feel a stretch in your shoulders and chest.
7. Hold this position for a comfortable period, for example 10 seconds.
8. Step back and relax.



Mouth breathing all the time may result in symptoms, such as:

- ❖ A feeling of not being able to breathe deeply, or get a big breath in.
- ❖ Dry mouth, bad breath, and/or gum disease.
- ❖ An annoying cough.
- ❖ Frequent chest infections.
- ❖ Difficulty in swallowing, eating, and drinking.
- ❖ Snoring and/or poor sleep.

There are times when you may need to breathe through your mouth, such as:

- ❖ When your nose is blocked.
- ❖ When you are exercising.
- ❖ When you are feeling stressed or anxious.
- ❖ When the shape and size of your jaw, teeth or nose stop you from breathing through your nose.

The nose:

- ❖ Acts as a filter, trapping small particles such as pollen and dust.
- ❖ Warms and humidifies the air, preventing dryness in the airways and lungs.
- ❖ Controls the speed of your breathing and in turn makes diaphragmatic breathing easier.
- ❖ Helps with speech and voice control.
- ❖ Helps with eating and drinking.

Breathing with your Nose:

If you find closing your mouth and breathing through your nose difficult - do not worry. You may only manage 2-3 breaths through your nose at a time. The more you practice nose breathing, the easier it will become.

If you feel that you are breathing more through one nostril than the other – don't worry, this is normal. Our nose has a smart way of cleaning itself. While one nostril is going through the cleaning process, the other nostril does all the work. They swap every 90 minutes or so.

Aim to practice breathing through your nose little and often. You may want to:

- ❖ Change the position you are in when practicing nose breathing (lying down, sitting on a chair, standing).
- ❖ Set yourself targets to increase the number of breaths you can manage.
- ❖ Set yourself targets to increase the length of time you can manage to breathe through your nose.

If your nose is blocked, and has been blocked for some time, speak to your GP. Things that may help include:

- ❖ Humming a song for 1-2 minutes a day
- ❖ Nose sprays
- ❖ Sinus clearing medication
- ❖ Nasal Rinsing. You can find about more about this here: <https://www.nhsinform.scot/illnesses-and-conditions/ears-nose-and-throat/allergic-rhinitis#treating-allergic-rhinitis>

GUIDE TO DIAPHRAGMATIC BREATHING

1. Lie on your back (on a sofa or your bed) with a pillow under your head and knees.
2. Close your mouth and try to breathe through your nose.
3. Let your face relax.
4. Keep your tongue still and sitting behind your top teeth.
5. Place one hand on your tummy and one hand on your chest.
6. Let your shoulders, chest and arms drop until they feel heavy.
7. Relax your legs until they feel heavy.
8. Aim to practice every day, for example for 10-20 minutes.

As you relax, you should notice that your tummy begins to rise as you breathe in and falls as you breathe out. This is diaphragmatic breathing. If you do not feel this, let your shoulders, arms, chest and legs relax until they become heavy.

To help you feel your diaphragmatic breathing you may find it useful to place a small weight over your upper tummy, such as a wheat bag, hot water bottle or a book.

As you get used to diaphragmatic breathing, you will notice a short pause between breathing out and breathing in. This is normal. Once you feel comfortable with diaphragmatic breathing lying down, try it when you are sitting and standing.

Diaphragmatic breathing should feel relaxed and easy. This is how your body wants to breathe. The more you practice diaphragmatic breathing, the easier it will become.



TIPS FOR MANAGING YOUR BREATHLESSNESS

Stay well hydrated

Pursed lip breathing:

This exercise can be used at any time to help you stay in control of your breathing. You can also use it while you are doing something that makes you breathless and it will help you to feel less out of breath.

How to do it:

- ❖ Breathe in gently through your nose.
- ❖ Then purse your lips as though you were going to blow out a candle or whistle.
- ❖ Blow out with your lips in this pursed position. Try to blow out for as long as is comfortable and donot force the air out your lungs.

BLOW AS YOU GO

You can use this exercise while you are doing something that makes you breathless. Breathe in before you do the activity that makes you short of breath. Then breathe out while doing the activity. For example, when lifting a heavy bag, breathe in before you lift the bag and then breathe out through pursed lips as you lift the bag – **'blow as you go'!**

Here are some other examples of when to use 'blow as you go':

- ❖ As you stretch your arms above your head to reach for something
- ❖ As you reach for something – such as a glass of water by your bed
- ❖ As you reach or bend down
- ❖ As you lift a heavy object or weight
- ❖ As you step up
- ❖ As you stand up
- ❖ During the most difficult part of any action

KEEP IT SIMPLE

All this information can be a lot to take in so the easiest way to remember what good breathing is, is to remember these 3 simple words:

NOSE

- breathe in and out through your nose as much as possible

LOW

- Breathe at your tummy

SLOW

- Slow and Quiet breath out

The positions described on the next page will help you get your breath back when you have done too much and you are feeling short of breath.

High side lying:

- ❖ Lie on your side, with a few pillows under your head and shoulders. Some people like to use a foam wedge instead.
- ❖ A pillow between your waist and armpit can stop you sliding down the bed.
- ❖ Make sure the top pillow supports your head and neck.
- ❖ Your knees and hips should be slightly bent.
- ❖ Depending on your lung condition, it may be better to bend both of your legs or just your top leg.



Sit upright:

- ❖ Sit upright against the back of a solid chair.
- ❖ Rest your arms on the chair arms or on your thighs.
- ❖ Drop your shoulders and let go of any tension/tightness in your body.

Sitting leaning forward:

- ❖ Sit leaning forward from your hips with your elbows resting on your thighs / knees.
- ❖ Drop your shoulders and let go of any tension in your body.

Sitting Leaning forward at a table:



- ❖ Sit leaning forward from your hips with your elbows resting on a table.
- ❖ You can also put a few pillows on the table to rest your head on.
- ❖ Drop your shoulders and let go of any tension in your body.

Lean forward standing up:



- ❖ Lean forward resting your elbows on a wall, a windowsill, or other solid surface.
- ❖ You could lean on a walking stick or a long umbrella if you use one.
- ❖ You can lean on a trolley while you are out shopping.
- ❖ Drop your shoulders and let go of any tension in your body.

How To Help Your Cough?

Why is cough important?

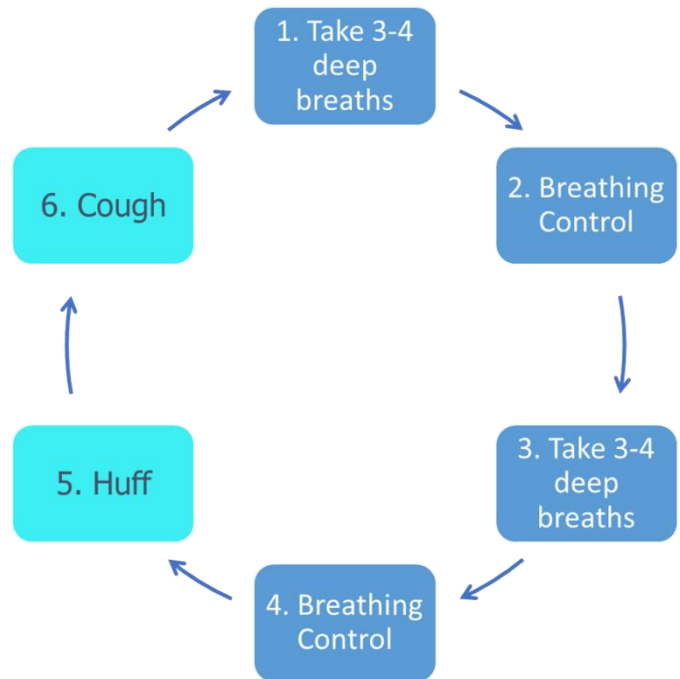
- It protects your windpipe.
- It clears phlegm/mucus and other things that may cause your airway and lungs bother.

Two types of cough:

- Wet, where you cough up phlegm
- Dry, and happens often throughout the day where you don't cough anything up. This type of cough is often not helpful as it has no purpose.

If your cough is wet:

If you can feel and hear gargling noise when you breathe or cough and you cough up phlegm/gunk, the exercise on your right will help you clear this away. If you do this exercise a few times a day every day, you will feel like your chest is clearer and you will feel less breathless.



Breathing Control
<ul style="list-style-type: none"> gentle, relaxed breathing think of breathing through your nose and tummy drop your shoulders and lets go of any tension close your eyes if this helps you relax

Deep Breathing
<ul style="list-style-type: none"> breathe in slowly through your nose and your tummy gently breathe out by allowing air to escape you, dont force it out repeat 3-4 times only to ensure you dont feel dizzy what you want to achieve here is a gentle `rattle` on a breath out

Huff
<ul style="list-style-type: none"> take a deep breath in through your nose open your mouth breathe out forcefully as if you are steaming up a mirror or glasses to clean them repeat 1-2 times always finish on a cough stop when your huff is dry

WHAT CAN CAUSE MY UNHELPFUL, DRY COUGH?

Coughing can be one of the main symptoms of Covid-19, and it can go on long after the virus has gone from your body. While the reason for this is still being looked into, it is thought that after Covid-19 your body's trigger for coughing (the thing that brings it on) is much more sensitive than before. This can make you cough even though there's nothing to clear from your chest or throat.

Trying to stop this unhelpful and unwanted cough is like trying to stop yourself from scratching an annoying itch. You know if you start scratching it – it will itch more and then you'll scratch more. It's the same with an unwanted cough – if your cough is brought on by a trigger you cough to clear your throat. If you continue to cough over a long period of time, your airways will become more sensitive so then even the smallest trigger will make you cough and make it harder to stop.

Ways to help your unwanted cough:

- ❖ Drink regular, small sips of water.
- ❖ Work on your breathing (see Breathing Section – NOSE, LOW, SLOW).
- ❖ Suck boiled sweets to keep your throat wet.
- ❖ Speak slowly in short sentences.
- ❖ Anxiety can cause you to develop a nervous cough, so be aware of what makes you anxious and worried (for example speaking in public).
- ❖ Take your medicine/pills as prescribed.
- ❖ If you use them, make sure you rinse and gargle with water after using inhalers, especially your preventer inhaler.
- ❖ Don't use strong perfumes and other things which make you cough more.
- ❖ Don't have caffeine and spicy foods if they make you cough or cause indigestion/heartburn which are common triggers for cough.
- ❖ Don't eat too much at a time as this can also cause heartburn or indigestion.

When do I need to seek advice from a doctor?

- ❖ If you feel unwell.
- ❖ If you are feeling more breathless than normal.
- ❖ If your cough is different than usual, you may be coughing more or less than is usual for you.
- ❖ If you are worried about your symptoms and they are not getting better.

Managing Voice Problems

Voice problems can include hoarseness, weak breathy voice, strain, overly high or low pitch, or any noticeable change in your speaking or singing voice.

As you recover from Long Covid you may find that your voice has changed. There are some reasons for this:

- ❖ Cough (please see the 'ways to help unwanted cough' section of this workbook, page 35).
- ❖ Shortness of breath (please see the 'managing breathing difficulties' section of this workbook, page 27).
- ❖ Dry throat.
- ❖ Heartburn.
- ❖ Fatigue (feeling very tired).
- ❖ Stress leads to muscle tension and sometimes you'll get a feeling of having a 'lump in your throat'.
- ❖ Neck and shoulder tension can affect your voice and swallowing.
- ❖ If you were in an intensive care unit and were ventilated.

WHAT CAN I DO TO HELP MY VOICE?

- ❖ Drink plenty of fluids. Stop or cut down caffeinated coffee, tea, alcohol and fizzy drinks.
- ❖ Speak at a normal volume using a gentle voice. Do not whisper or shout.
- ❖ Avoid throat clearing. Swallow instead.
- ❖ Stop or cut down smoking or vaping.
- ❖ Heartburn can change your voice. Don't eat big meals, especially late at night. Speak to your GP or pharmacist about what medicines might help with heartburn.
- ❖ Try steam inhalation 2 times a day for 5-10 minutes. Fill a bowl or large mug with heated water. Place your face over the bowl or mug and put a towel over your head. Breathe normally and allow the steam to go into your nose and mouth. Do not use menthol crystals.
- ❖ Do not try and talk above any loud background noise at home, work, social or sport events.
- ❖ Avoid using the telephone too much.
- ❖ Do not sing if you have voice problems.
- ❖ Rest your voice when you can. Plan some quiet time throughout the day.
- ❖ Do not clench your teeth. Instead, loosen your jaw, soften and drop your shoulders and take a low diaphragmatic breath before speaking.

If you follow this advice, your voice will hopefully get better over time.

If it does not get better or if it gets worse, you should speak to your GP or Speech and Language Therapist for advice. You may need more help.

Nutrition

GETTING YOUR APPETITE BACK TO NORMAL

It might be hard to eat after Covid-19. You might find you are eating too much or too little. You might also not be interested in eating because you feel tired or weak. There are a number of things that could make it hard or easy to eat.

Some of these signs may include:

- ❖ Change in taste and smell.
- ❖ Smaller or bigger appetite.
- ❖ Eating smaller amounts.
- ❖ Feeling full too quickly.
- ❖ Not enjoying your food and eating.
- ❖ Dry mouth.
- ❖ Swallowing problems. This might happen if you had a tube placed in your nose or throat when you were in an intensive care unit.
- ❖ Stomach problems, such as diarrhoea, feeling sick, bloating and indigestion.
- ❖ You may find that you have lost a lot of weight after having Covid-19. You may now be underweight and need to put on some weight. Even if you are a healthy weight or you are overweight you may still feel weaker. This is because you have lost muscle.
- ❖ To help you recover after Covid-19, you may need to eat more than you did before. This is because you may need to put on weight, build some muscle or increase your energy levels so you can be more active.

Tips for a poor appetite:

- ❖ Eat whenever you feel hungry – like having cereal at midnight.
- ❖ Try different foods. You may find new foods that you like or that you enjoy, that you didn't like before.
- ❖ Keep snacks close to you, such as on the bedside table or coffee table.
- ❖ Do not drink just before meals as this may fill you up and make you less hungry. Only drink before meals if you need help with swallowing.
- ❖ Salads and vegetables are an important part of a healthy diet, but do not eat too much with each meal if they are filling you up quickly.
- ❖ Avoid fizzy drinks as they can make you feel full up.
- ❖ Let others help with cooking and shopping whenever possible.
- ❖ Ready meals are a useful back up if you don't feel like cooking and can be nourishing.
- ❖ When you are stronger and able to cook for yourself, you could cook food in advance and freeze it for when you are not feeling so well.
- ❖ If a full plate of food seems too much start with eating little bits of food often. Eat snacks between meals and before bed.
- ❖ Eat every 2-3 hours, so you are eating 6 times a day.
- ❖ Eating little and often will slowly increase your appetite

WHAT CAN I DO TO HELP MY GUT HEALTH?

Common gut problems in Long Covid are feeling sick, bloating, pain and diarrhoea. These are irritable bowel syndrome (IBS) type symptoms. If these carry on speak to your doctor, as it is important to rule out other reasons like Coeliac disease. Below are some useful tips to help you manage those symptoms:

- ❖ Eat three regular meals a day.
- ❖ Do not skip any meals or eat late at night. Smaller meal sizes may help you feel better.
- ❖ Do not drink any more than two units of alcohol every day – this is a small glass of wine or a pint of normal strength beer or lager. Have at least two days each week when you don't drink alcohol at all.
- ❖ Limit drinks with caffeine like coffee or tea - no more than two mugs (three cups) a day.
- ❖ Limit the number of fizzy drinks you have.
- ❖ Drink at least eight cups of water or other drinks that don't have caffeine, for example herbal teas.
- ❖ Cut down on rich or fatty foods. These include chips, fast foods, pies, batter, cheese, pizza, creamy sauces, snacks such as crisps, chocolate, cake and biscuits, spreads and cooking oils, and fatty meats such as burgers and sausages.
- ❖ Limit the number of ready meals you eat and try and cook using fresh ingredients where possible.
- ❖ Try not to have more than three portions of fresh fruit each day (one portion is 80g) and have two or more portions of vegetables.

Please use the links below to give you more information on the following topics:

For advice on fortifying your diet if you have a poor appetite

NHS Inform – Malnutrition

<https://www.nhsinform.scot/illnesses-and-conditions/nutritional/malnutrition/>

For advice on weight loss

British Dietetic Association – Weight Loss

<https://www.bda.uk.com/resource/weight-loss.html>

For advice on Healthy Eating or IBS

British Dietetic Association – Long Covid and diet

<https://www.bda.uk.com/resource/long-covid-and-diet.html>

NHS Inform – Eating well Guide

<https://www.nhsinform.scot/healthy-living/food-and-nutrition/eating-well/eatwell-guide-how-to-eat-a-healthy-balanced-diet/>

NHS Inform – Irritable bowel syndrome

<https://www.nhsinform.scot/illnesses-and-conditions/stomach-liver-and-gastrointestinal-tract/irritable-bowel-syndrome-ibs>

Managing Swallowing Difficulties

Covid-19 can sometimes make it uncomfortable to swallow.

You might have been in an Intensive Care Unit (ICU) and needed help with your breathing. If you have been in the ICU you may have weak mouth and throat muscles, swelling in your throat and/or pain because of the intubation tube you had down your throat helping you to breathe. Stress can lead to muscle tension and give the feeling of a 'lump in your throat', making it more difficult to swallow.

People with swallowing problems may have:

- ❖ Choking and coughing when eating or drinking.
- ❖ Gurgling, or a croaky voice after swallowing.
- ❖ Feeling the need to cough and clear your throat after swallowing.
- ❖ Frequent chest infections.
- ❖ Food 'sticking' in the throat.
- ❖ Difficulty 'getting food over'.
- ❖ Taking a long time to eat and drink.

WHAT CAN I DO TO IMPROVE MY SWALLOWING?

- ❖ Always sit upright when eating.
- ❖ Don't tip your head back.
- ❖ Make sure that you are fully awake when eating.
- ❖ Take your time – do not rush your meals. Rest if feeling breathless or tired.
- ❖ Try softer foods, which are often easier to eat.
- ❖ Make sure you have good dental health – brush your teeth twice a day and visit your dentist.
- ❖ Do not talk when you are eating. Think about eating and swallowing.
- ❖ Take small bites or sips.
- ❖ Drinking thicker drinks like shakes and smoothies may help.
- ❖ Don't use straws unless your therapist has told you to.
- ❖ Don't lie down straight after eating, as this can cause reflux – this is when your stomach acid comes back up towards your throat. It can give you a burning pain in your chest.

If your symptoms don't go away after you follow this advice or if they get worse – please speak to your GP or Speech and Language Therapist.

Change Or Loss Of Smell And Taste

Covid-19 can often cause a change in your taste and smell. Most people take around four weeks to get better, but for some this problem can last longer.

TASTE

A loss of taste can happen on its own, or you may get a change in your sense of smell as well. We don't know why some people lose their taste. These changes won't last forever, but for some people it may take weeks or months to get better.

How can I improve the taste of food?

- ❖ Choose foods that you enjoy the most
- ❖ Keep your mouth clean and healthy
- ❖ If cooking smells bother you, choosing cold foods may help
- ❖ Try out different food flavours and textures
- ❖ Adding strong flavours like herbs, horseradish sauce, mustard, pickles, apple/cranberry/mint sauce can help
- ❖ If you have a metal taste in your mouth you could try using – plastic cutlery and cups. Some people find this helps them.
- ❖ Sucking boiled sweets may help freshen your mouth
- ❖ Don't eat spicy food

SMELL

Changes in smell linked with Covid-19 include:

- ❖ Loss of smell (anosmia)
- ❖ When things smell different and often not nice (parosmia)
- ❖ Smelling things that are not there; commonly burnt toast or smoke (phantosmia)

Having smells that were nice before and are now nasty is very common after Covid-19. The good news is that this is a sign that your smell is coming back; this can last for months but should get better. Each smell is made up of thousands of tiny parts. People who have parosmia and phantosmia pick up on the stronger (and sometimes nasty) smelling parts that you would not normally smell on their own. These are known as triggers.

What can I try if I have problems with sense of smell?

- ❖ Don't eat foods that have strong and nasty smells.
- ❖ Try eating plain foods – rice, bread, yoghurt, steamed vegetables.
- ❖ You could try unflavoured protein shakes.
- ❖ Order foods online so you don't need to go to the supermarket.
- ❖ Avoid eating foods that trigger the nasty smells like onions, garlic, fried foods.

There are some things you can do to help your sense of smell if you have total smell loss. Smell training is something that can help people with loss of smell.

How do I do smell training:

- ❖ You will need some jars and essential (aromatherapy) oils. Research shows that using four essential oils (rose, lemon, clove and eucalyptus) gets the best result, but you can use more oils if you would like to.



- ❖ Pour a few drops of the oil in a jar and keep it in a handy place. You can make few jars and place them in different rooms around your house so you can do the training a few times a day. You can buy ready-made smell kits in some shops.
- ❖ Smell each jar for 20 seconds. Rest for a few seconds and then move on to the next jar. Do this a few times every day. When you sniff, take tiny little sniffs, not big deep breaths.
- ❖ Try to imagine the smell while you are sniffing and try to remember what it used to smell like. This is a really important part of the smell training.

If you require more information about taste loss – please follow the link below:

<https://abscent.org/>

Covid-19 And Emotions

In a crisis, support is available from:

Samaritans - Telephone 116 123 (UK) free to call with 24-hour support or online at <https://www.samaritans.org/?nation=scotland>

Breathing Space - Telephone 0800 83 85 87
Opening hours: Weekdays: Monday -Thursday 6pm to 2am
Weekend: Friday 6pm - Monday 6am

Contact your GP, or ring NHS 24 by dialling 111 - medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

MIND - Visit <https://www.mind.org.uk/> for information and support on mental health.

Living with the lasting effects of Covid-19 can be scary, especially when your symptoms don't go away or are changing. You might need to change the way you used to do things, and the amount of things you can do because of Long Covid. This can be a difficult adjustment, and getting used to managing your symptoms can be quite lonely, isolating, and frustrating which can affect your mood.

Many people who are living with Long Covid have a 'grieving period' to process these changes, and to work through any negative emotions they may have. These negative moods and emotions are a part of the journey for some people, and like the other symptoms of Long Covid, may last a long time for some, and be short lived for others.

If you experience a low mood or negative emotions that feel out of control, or will not go away, get in touch with your GP or Healthcare professional.

There are many ways in which Covid-19 may have changed your mood. Here are some of the ways:

Stress and a feeling of worry

- Around your recovery
- Your future
- Another infection
- Work, money

Low Mood

- Not meeting your friends and family
- Feeling alone
- Not wanting to do things you used to like

Anger and Frustration

- Wanting to recover faster
- Why me?

Trauma

- Nightmares and flashbacks from the time you have been unwell

How can I help my emotions?

There are a lot of things you can do to try and help the way you feel.

- ❖ **Caring for yourself:** Sometimes you can feel angry or wish you never had Covid-19 in the first place. You may think 'I am not good enough', 'I am worthless', 'I am such a hassle' and these feelings might make you want to hide away from others. Living with Long Covid is very difficult and sometimes it takes longer to recover. This does not mean that you are not good enough. You are doing the best you can to adapt! Try not to be harsh on yourself. Remember all the things you have accomplished since you got Long Covid and allow your body to take the time it needs to recover.
- ❖ **Get the help you need:** It is important to stay in touch with other people and speak to family and friends. Often, when we feel unwell, we tend to shut down, and avoid talking to others or doing the things we like. This can make us feel very alone and stuck feeling hopeless. Spending time with your loved ones and talking to them about your difficulties can be the help you need to start feeling better.

- ❖ **Focus on what you can change:** It may feel like your illness controls your life. Long Covid has probably affected your body and your ability to do things the way you used to. This can make you feel like your illness controls your life. However, although you might struggle to control the effect of Long Covid on your body, you still have control over how you want to live your life. It might take some adjustments but it is in your control. For example, you might not be able to stop from feeling tired when going out. However, you can continue to go out by making sure you take regular breaks or do activities that do not need any physical activity.
- ❖ **Try to do things that make you happy:** People like different activities. It depends on their fitness levels and what they are interested in. Think of the things you enjoy doing and put them in your diary.
- ❖ **Put off your worry:** It may feel that worry controls your life, and that you can't stop yourself from worrying. We will often try to push our thoughts away, but this usually does not work, as our worries seem to always return. Try to put off your worry rather than pushing it away. This can help you feel more in control over your worry, instead of your worry being in control of you. Please look at page 44 to learn how to put off worry.
- ❖ **Problem-solving:** It is possible that a lot of stressful things have happened to you because of Covid-19. For example: dealing with your work, house, money, illness. Such things may have made you worry about the future. Learning good problem-solving skills can help you find solutions to your problems, lessen worry, and get some control back over your life. Please look at page 45 to learn skills on problem solving.
- ❖ **Try not to hold back thoughts and feelings:** You may feel snowed under with your emotions. Some of us may try to avoid our thoughts and feelings because we are afraid we will not be able to manage them. But if we do that, we worry more. Remember, that we all have emotions, and we have the right to feel them, whether other people believe it's right or not. Emotions are normal, and they will become less strong if we accept them and talk about them, instead of pushing them away.

In the following sections, you can find some helpful tips to manage your emotions. Feel free to read through them and pick the one's you like the most.

PUT OFF YOUR WORRY

Worrying is normal, but it can become a problem if:

- ❖ It happens a lot.
- ❖ You can't stop worrying.
- ❖ You worry about things that have not happened yet. This means they cannot be solved at the moment.

When you worry for a long time or when you worry a lot – this can make you more nervous and make you worry even more. In turn this may stop you from positive thinking and action.

When a worry thought pops into our head we tend to do two things:

1. We pull it closer - We keep thinking about what makes us worry, hoping to solve it. Instead, because our worry has not happened yet, or may never happen, we get stuck in having negative thoughts about the future that we cannot control or solve.
2. We push it away. We try to get rid of the worry by telling ourselves to stop thinking about it! It seems that the more we try to push it away and not think about it the stronger the worry comes back. What if I told you to not think of a pink elephant? The first thing you probably did was start imagining a pink elephant! It's the same if we try not to think about the thing that is worrying us.

No matter which of these two things you do it is very likely that both will stop you from thinking about your day-to-day activities and the things you like doing. So rather than trying to pull it closer or push it away try to put off thinking about your worry for a while.

HOW DO I PUT OFF MY WORRY?

Set a worry time

Set a time during the day to think about your worries. This could be anytime during the day for any set length of time (Try no more than an hour). Don't do it too close to bedtime as it might stop you from sleeping.

Put-off

During the day, if you notice a worry popping into your head, instead of pushing it away or pulling it closer, you can let the thought come into your head. Then tell yourself you will put off thinking about it for now and give your attention to it during worry time.

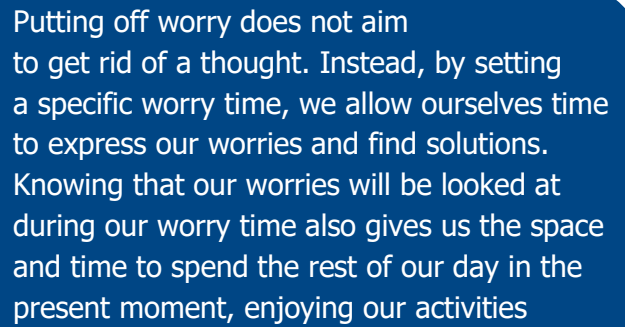
You can say to yourself something like 'I just had a worry thought of...This is okay. I will let it go for now and I will come back to it during my worry time'.

Once you decide to put off your worry, bring your attention back to the present moment and the thing you were doing. If another thought or the same thought pops into your head, put it off again. You can also write your worry in a notepad for you to remember later.

During worry time

Think about the worries you had during the day and focus on the ones that are still important. If they are no longer important, you can cross them off your list.

If you are worrying about something that is a problem for you now, then you can use the problem-solving technique on the next page to find solutions.



Putting off worry does not aim to get rid of a thought. Instead, by setting a specific worry time, we allow ourselves time to express our worries and find solutions. Knowing that our worries will be looked at during our worry time also gives us the space and time to spend the rest of our day in the present moment, enjoying our activities

If you can't think of a way to deal with your worry or you are worrying about something that is not a problem just now, you can do the following:

- Write the worry on paper and try asking yourself questions like 'Is it possible that my worry may not become true?', 'What else could happen? (a positive one maybe?)', 'How could I cope if the worry did become true?', 'What would I say to a friend going through the same thing?'. You can also talk about these questions with your love one's.
- You can use meditation techniques on page 52 to help you with letting go and accepting your thoughts.

PROBLEM SOLVING

Before starting, it is important to think if you are able to solve your worry. Ask yourself the following questions:

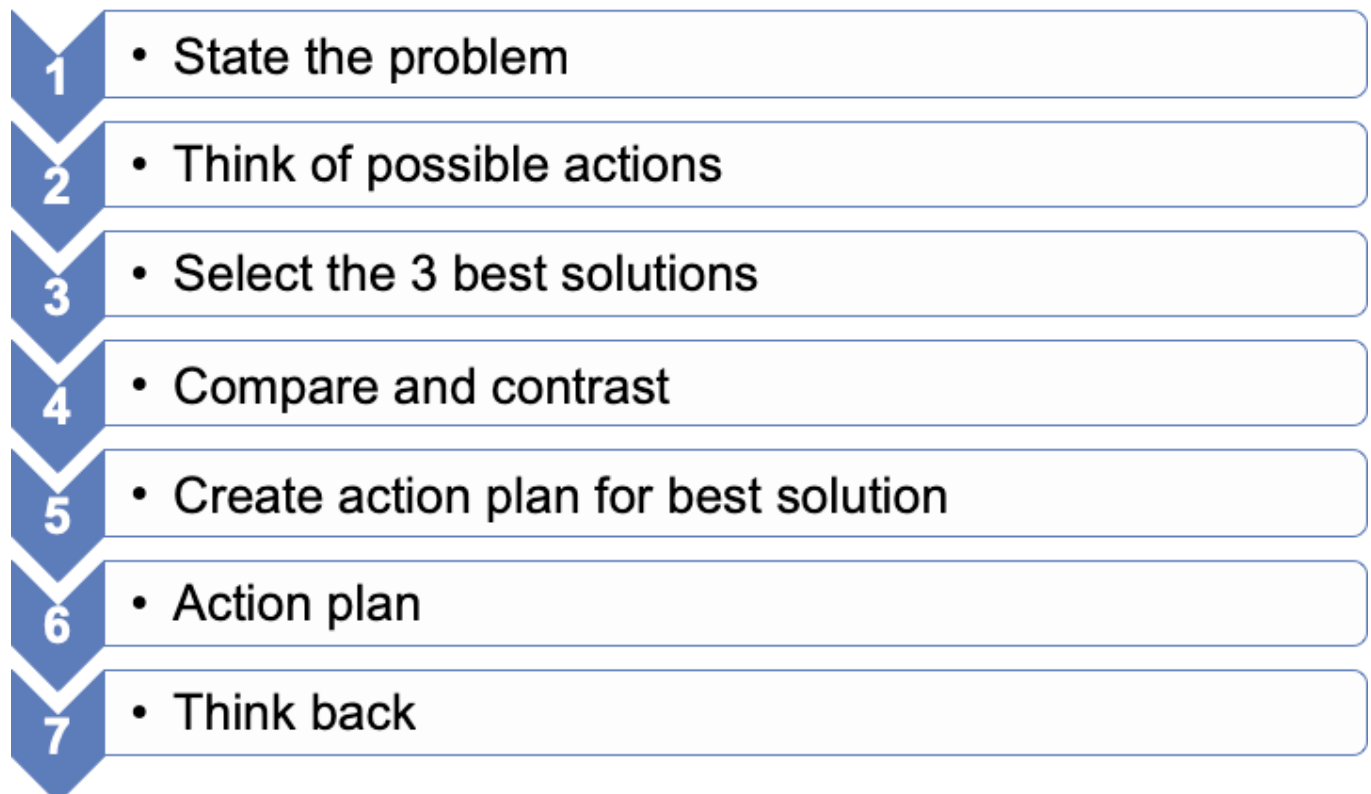
- ♦ Is this an actual problem?
- ♦ Is this problem happening right now?
- ♦ Do I have any control over this problem?

If your answers are **yes**, then problem-solving can be a helpful.

Here are some examples of problems to solve and the ones you will struggle to solve:

SOLVABLE WORRIES – things I can change	UNSOLVABLE WORRIES – things I can't do anything about
I am unable to drive to my appointment.	What if my illness gets worse?
I had a fight with my husband/wife/partner.	What if I can't return to work in a years' time?
I can't afford to pay my rent this month.	What if my landlord increases my rent?

How do I do it? Let's look at each step in more detail. An example will be used throughout this exercise.



STATE THE PROBLEM

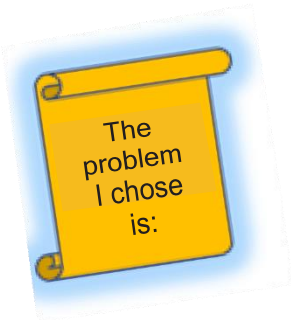
The first step is to say what the problem is. Remember that we are only going to work on problems you can solve. This means they are happening right now, and we can control or change them. We might want our illness to go away for example, but this is not a solvable problem as we can't always change or control it. Managing our physical illness, however, can be something we have control over. Be as clear as possible when you say what the problem is. Don't think about how you feel, but think about the actual problem. Focus on the situation, behaviour and what actually makes this thought a problem.

Example:

'I want my illness to go away' is not a specific or solvable problem. Your illness won't just go away.

'I become breathless when I clean the house' is a solvable problem, that describes both the situation (when I'm cleaning), and the behaviour (I get breathless). Knowing exactly what the problem is can help us take action.

Please write down the chosen problem:



.....

.....

.....

.....

THINK OF POSSIBLE ACTIONS

Try and think of possible actions you can take to solve the problem. Try not to choose the best option yet. Just write down as many ideas as you can think of.

Here is an example:

THE PROBLEM	POSSIBLE ACTIONS
'I feel breathless when I clean the house'	I can ask my partner to do clean the house. I can do two household chores per day and no more. I can hire someone to clean my house weekly. I can move to a smaller house. I can buy a robotic vacuum.

Write down you own problem and possible actions

MY PROBLEM	POSSIBLE ACTIONS

SELECT 3 BEST SOLUTIONS

Pick the three solutions you think would work best

Example:

1. I can ask my partner to clean the house
2. I can do two household chores per day
3. I can hire someone else to clean the house.

Try writing down your three preferred solutions

.....

.....

.....

COMPARE AND CONTRAST

Think which action will best solve the problem. Look at the 'good points' and 'bad points' of each solution, compare and contrast them. Which one seems to be the best option at the present moment?

Here is an example:

POSSIBLE SOLUTIONS	GOOD POINTS	BAD POINTS
1. Ask my partner to clean the house	<ul style="list-style-type: none"> • I will not be breathless • It is free 	<ul style="list-style-type: none"> • I will lose my independence • My partner has already a lot on their plate • I will not learn how to manage my own physical illness. • I will feel like a burden.
2. I can do two chores a day	<ul style="list-style-type: none"> • I will be independent • I will learn to manage my physical illness • I will continue to have control over household chores 	<ul style="list-style-type: none"> • I will get breathless and tired
3. I can hire someone to do it	<ul style="list-style-type: none"> • I will not be breathless • I will not need to rely on my partner 	<ul style="list-style-type: none"> • It is expensive • I will not be independent • It might not be a realistic solution for the long-term

Now it is your turn to compare and contrast your options:

POSSIBLE SOLUTIONS	GOOD POINTS	BAD POINTS
1)		
2)		
3)		

CREATE ACTION PLAN FOR BEST SOLUTION

Think of the 'good points' and 'bad points' you have come up with for each solution. Pick the one you like the most and create an action plan. Write down your plan of action – think about when you'll do it and the way you will do it. The action needs to be:

- 1) **Specific:** The action needs to be very clear. For example: Every Monday I will do two household chores: washing the dishes and hoovering the living room. I will do the hoovering in the morning, and the dishes in the afternoon or evening. I will rest in between.
- 2) **Realistic:** Try to choose an action that is easy to do rather than something that is too hard. If you make it too hard then you might find that you cannot finish the task. This may make you disappointed or make you worry. It is better to set small actions, rather than big goals.

Example: 'I will Hoover the whole house and do the dishes'. This might be too hard if you are feeling very breathless. Starting with just hoovering the living room is a more realistic goal. It means you're more likely to finish that task and you'll feel proud of yourself.

You might have decided to pick more than one solution. If so, then create an action plan for each. If you find that your chosen solution is not working, you can go back and look at the other options you chose, or start the problem solving exercise again. Pick the solution you find the best and create an action plan. If you have selected more than one solution, then create an action plan for each.

Create your own action plan:

ACTION STEPS	WHO?	WHEN?

CARRY OUT THE ACTION

Go ahead with your action as you planned it.

THINK BACK

Think back on how good your action plan was? Was it enough or do you need do to another one? Did it work or do you need to change it? What did you learn from it?

Try to write down your thoughts and feelings as a result of following the plan. Did it help you worry less?

RELAXATION

When you are stressed, your body will naturally become tense. You may feel your muscles becoming tighter, your heart beating faster, and your breathing becoming harder. You may also have a headache, back pain, and higher blood pressure.

Relaxation techniques can help your body feel less tense can help you worry less. Relaxation techniques will help your muscles and your mind feel more relaxed. There are a number of different relaxation techniques you can try to help reduce tension and relax your mind.

Remember:

- 1) You have to practice often. If you have never done relaxation before then your body and your mind will be learning new skills. It takes practice to feel confident using them.
- 2) Try to do a relaxation exercise when you feel calm, to make sure you can focus on it. The more you practice, the easier you'll find it to use relaxation techniques when feeling very stressed.

Below you can find different types of relaxation exercises. Feel free to explore them and use the one's that you find the most helpful.

Progressive muscle relaxation

<https://www.youtube.com/watch?v=86HUcX8ZtAk&t=291s>

Relaxed Breathing

<https://www.youtube.com/watch?v=jPMw2PIqJC8&t=11s>

Guided imagery

https://www.youtube.com/watch?v=t1rRo6cgM_E

Safe place

<https://www.youtube.com/watch?v=G1bxxiiXc48>

HOW TO COMFORT YOURSELF

There are things we all do to help us feel calm and relaxed when we're feeling emotional. These activities usually involve our senses, and they can be quick and helpful ways to feel calmer and more in control of our emotions.

Think about what you do when you are feeling stressed. Do you have a shower? Cuddle under a blanket? Have a cup of tea? Below you can find examples of such activities.

Visual

- ❖ Looking at photographs of happy memories
- ❖ Looking at pictures of relaxing or fun places
- ❖ Looking at the nature around us
- ❖ Looking at art
- ❖ Watch your favourite TV show or movie

Hearing

- ❖ Listening to music
- ❖ Listening to the sound of nature, such as waves or bird sounds
- ❖ Listening to an audio-book or a guided imagery exercise
- ❖ Listen your favourite TV show or movie

Smell

- ❖ Smell scented candles
- ❖ Favourite perfume, body mist, body cream
- ❖ Cook a meal that smells delicious
- ❖ Go to a place where you might enjoy the smell (park, flower shop, perfume shop, bakery, restaurant)

Taste

- ❖ Cook or buy your favourite meal and eat it slowly
- ❖ Make a cup of coffee/tea/smoothie
- ❖ Chewing gum with your favourite flavour
- ❖ Eat some fruit

Touch

- ❖ Cuddle your pet
- ❖ Hug someone who you care about
- ❖ Cuddle under a blanket
- ❖ Touch/wear any fabric that seems soothing to you (something smooth, velvety, fluffy)
- ❖ Hot/cold showers
- ❖ Hot water bottle

Think about what you find relaxing and try to do those activities when feeling stressed. It can be helpful to use techniques that have worked before by making you feel safe and relaxed.

Feel free to ask friends and family for their own ideas but remember that what works for one person does not work for others.

MINDFULNESS

Long Covid symptoms can affect our lives in ways we find very upsetting. We might have lots of worrying thoughts. This can often be about the past or things in the future. These thoughts can grab our attention and stop us from doing things we enjoy. This habit of worrying can sometimes make us feel low in mood.

It is helpful to know when we have lots of worrying thoughts – and also strong feelings. If we are aware of this, we can switch our attention to activities that either make us feel good about ourselves or that are meaningful. Taking time in our day to pay attention to our thoughts, feelings and surroundings in the moment is called **mindfulness**.



Mindfulness is a good thing to try practice. Let's try some:

1. Sit or lie in a comfortable position.
2. Notice the touch of your body on the seat, how does each part feel?
3. Pay attention and notice your breath – don't worry about HOW you're breathing right now, just FEEL it. Where do you feel the air moving when you breathe?
4. Notice how you feel. Are there any emotions coming up? Are there any thoughts coming up?
5. Notice how they feel but try not to do more than that just notice it.

This is a simple routine of mindfulness – just noticing how things are feeling – being mindful of them.

It is important to notice all thoughts and feelings. Not just the happy or sad ones but everything in between. Remember, when practicing mindfulness, you don't have to do anything with your thoughts and feelings or emotions that come up – you just notice them and then let them go.

Below is a link for a mindfulness activity:

Meditation for Beginners featuring Dan Harris and Sharon Salzberg

<https://www.youtube.com/watch?v=C-sFh5CWsQo>

The mind can be such a confusing and tricky thing! To help explain your emotions and why it can be important to slow down and pay attention to what is going on, here is a video on the evolution of the mind:

The Happiness Trap: Evolution of the Human Mind by Dr. Russ Harris

<https://www.youtube.com/watch?v=kv6HkipQcFA>

VALUE BASED LIVING

Managing Long Covid symptoms can take over our lives. We might become too focused on finding a way to deal with our symptoms so we can continue on with our lives and normal activities. These feelings are normal as it is a big part of our lives. Unfortunately, it can mean that we may lose track of what is important to us.

Doing the things that matter to you can help improve your mood and help you to continue to live a rewarding life. To do this, we must know what our values are.

Values are statements about how we want to behave and what we want to be doing with our lives. We can use these values to help guide us through life when we need to make decisions and plan activities.

It is helpful to focus on our values rather than our goals because it gives us more choice, freedom and flexibility in how we go about our day. This is important if our Long Covid symptoms are making us very upset or is stopping us from doing the things we enjoy.

Let's look at the example of 'Anne':

'Before having Long Covid I used to enjoy walking every week with my friend. This helped both my physical and mental health. Now I can't do this I feel very down, as it is just too tiring for me.'

Try to think about or write down what values are behind why Anne loves walking with her friend:

Examples of what values could be part of this activity are: connection, adventure, communication, friendship.

Now with a values approach let's see what Anne does now:

'It was not until I thought about it, being out in the open air somewhere new and having that connection with my friend was what mattered to me. We now meet somewhere for a picnic, snack or coffee; we've gone to so many new spots and still enjoy the time together like before.'

Another helpful way to start identifying your values is by reflecting on times when you felt really good about yourself and really confident that you were making good choices. You could ask yourself the following questions:

1. When was I the happiest?
 - ❖ What was I doing during this time?
 - ❖ Who was I with?
 - ❖ Where was I?

2. When was a time that I felt proud?
 - ❖ Why was I proud?
 - ❖ Did anyone else share my pride?
 - ❖ What other factors contributed to me feeling proud?

3. When was a time that you felt most fulfilled and satisfied?
 - ❖ What need or desire was fulfilled?
 - ❖ How and why did the experience give your life meaning?
 - ❖ What other factors contributed to your feelings of fulfilment?

4. Why is each experience important and memorable?
 - ❖ What do you think some of the values are underpinning these experiences?

**FOCUS ON
VALUES**
rather than goals

Once values have been identified, think about how you can try do activities with these and your symptoms in mind.

You will also find below a link to videos relating to values and taking life into a meaningful direction.

The Choice Point: A Map for a Meaningful Life by Dr. Russ Harris:

<https://www.youtube.com/watch?v=OV15x8LvwAQ>

Values vs Goals by Dr. Russ Harris

<https://www.youtube.com/watch?v=T-IRbuy4XtA>

Postural Orthostatic Tachycardia Syndrome (POTS) And Other Forms Of Dysautonomia

If you have POTS or another form of dysautonomia you should be getting individual treatment by a member of the health team – this section is for information only and to help you to manage your problems.

What is dysautonomia? (problem with your body's automatic system)

It is a term used to describe a number of medical problems that cause the Autonomic Nervous System (ANS) to not work properly.

The ANS manages automatic body functions that we do not have control over like heart rate, blood pressure, and digestion.

The ANS has two parts: the sympathetic nervous system and parasympathetic nervous system. They work together to balance our body's actions. The diagram below shows many of the different actions that are managed by ANS.

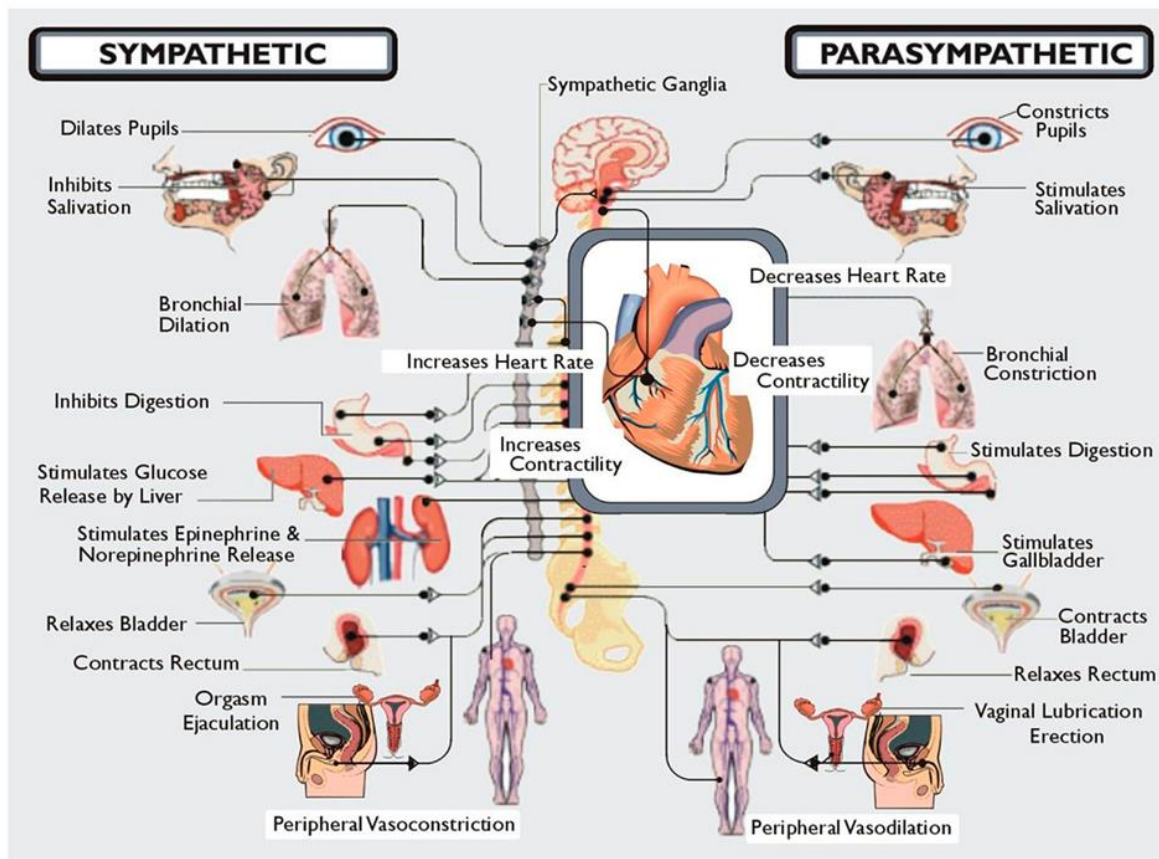


Image Credit: © Vinik (2012) The conductor of the autonomic orchestra. doi: 10.3389/fendo.2012.00071

The Sympathetic Nervous System manages the 'fight or flight' action and the Parasympathetic Nervous System manages the 'rest and digest' action.

Dysautonomia happens when these systems are out of balance, and often the sympathetic nervous system starts to work too hard. This can be triggered by illnesses like Covid-19.

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS) - Feeling Unwell When You Stand Up

One of the more common dysautonomia conditions is Postural Orthostatic Tachycardia Syndrome (POTS).

You may have heard of it while looking into your own Long Covid symptoms.

POTS can cause lots of different symptoms:



Image credit: DysautonomiaInternational.org

Many of these symptoms overlap with Long Covid symptoms.

Some people with Long Covid are developing POTS. Even before Covid-19 existed, the majority of people who developed POTS got it after an infection.

The diagnosis of POTS usually needs some tests.

Things which may make POTS symptoms worse:

- ❖ Time of day. Symptoms tend to be worse in the morning, especially after waking up and getting out of bed.
- ❖ Quickly moving from lying or sitting to standing.
- ❖ Dehydration (not enough water in the body).
- ❖ Hot weather or hot surroundings.
- ❖ Alcohol which causes the blood vessels to get bigger, and lower blood pressure.
- ❖ Menstrual periods.
- ❖ Staying in bed or not moving much for a long time (becoming unfit).
- ❖ Standing for a long period of time (or sitting).
- ❖ Stimulants such as tea, coffee, alcohol and nicotine.
- ❖ Large heavy meals high in refined sugar.

How can I help my dysautonomia or POTS symptoms?

- ❖ Having a good sleeping habit (see 'managing sleeping difficulties' section, page 59)
- ❖ Pace yourself throughout the day. Try not to fit too much in – there will always be another day. Take your time and avoid rushing.
- ❖ If you have something more difficult to do: plan your activity, rest well before and leave time after to recover.
- ❖ Over time you will figure out when you can push yourself, and when you need to rest. Know that it is OK to rest when you feel that your body needs it.
- ❖ Avoid stress if possible. The autonomic nervous system is the body's fight/flight system and is triggered during periods of stress.

Here are the standard self-treatment tips for POTS:

- ❖ Increase your salt and fluid intake once your doctor has approved this (aim for 3L of fluids and 8 grams of salt per day)
- ❖ Try an abdominal binder or full length medical compression stockings - this will help reduce blood pooling in your lower abdominal area and legs, which can reduce POTS symptoms
- ❖ Eat smaller meals throughout the day
- ❖ Avoid excessive carbohydrates/refined sugars
- ❖ Avoid hot showers, consider using a shower chair or taking your showers before bed so you have time to lay down after the shower.

If you have a diagnosis of POTS or you want to find out more, please visit these websites for more information and advice:

<https://www.potsuk.org/>

<http://www.dysautonomiainternational.org/page.php?ID=95>

Dizziness

The word 'dizziness' means different things to different people; some use it to describe feeling lightheaded or off balance, while others use it to describe a feeling that their surroundings are spinning.

This can often make people to feel anxious or stressed. Stress can make you breathe quicker and more shallow, which can make you feel dizzy. If you are affected in this way, your symptoms may feel worse and you may need some help to manage this.

For more information on stress and anxiety please see previous section of this workbook.

It can be common after Covid-19 to have dizziness. This dizziness is often brought on by certain head positions or movements. Our balance system needs time to get used to movement again.

Sometimes people get into the habit of avoiding positions and situations that may bring on their dizziness. This can really slow down their recovery and may cause other problems. If your dizziness comes on with a specific movement such as turning your head side-ways, you might start to avoid turning your head, and start using only your eyes to look at something instead.

To help with this, slowly start to make the movements that are causing your dizziness. Make sure you do this when you are somewhere that feels safe and comfortable for you. An example of this is described in the box below.

Dizziness exercise:

Walk somewhere that you feel safe, like your hallway. Look slowly from side to side, turning your head as you walk. Then repeat looking up and down. Make sure it is also your head that moves, not just your eyes.

To make this harder – try it in a busier but safe place, such as a supermarket aisle when holding onto the trolley. Then build up to being able to do this outside.

Please note these exercises are supposed to work your balance system in different ways. Some of these exercises may make you feel slightly dizzy. Please do not worry if this happens as long as this is manageable for you. This should get better the more/longer you practice.

It is important to speak to a healthcare professional about your dizziness, as it could also be caused by other things such as:

- ❖ Ear condition
- ❖ Dehydration
- ❖ Some types of medication
- ❖ Low blood sugar levels
- ❖ Anxiety or stress
- ❖ Postural hypotension (a sudden drop in blood pressure upon standing)
- ❖ Iron deficiency (lack of iron)
- ❖ POTS (see previous section of this workbook, page 55)

If you have any hearing loss, constant tinnitus (ringing or other noises in one or both ears), worsening of your symptoms, or a new unusual pattern to them, contact your GP.

Managing Sleeping Difficulties

Some Sleep facts:

- ❖ An average adult sleeps for about 7 – 8 hours per night.
- ❖ Some people need more sleep than others to feel awake in the morning.
- ❖ It is not about how much you sleep but how well you sleep.

What happens when we fall asleep:

- ❖ During sleep, a person goes between Rapid Eye Movement (REM) and non-REM sleep cycles.
- ❖ Non-REM sleep is made up of light and deep sleep.
- ❖ Light sleep is the first stage of sleep where your eyes and muscles are not very active, and your body is being prepared for deep sleep.
- ❖ As you go into deep sleep your brain and muscles stop being active, your blood pressure decreases and your heart and breathing slow down.
- ❖ If you are woken from a deep sleep you may be confused and difficult to waken.
- ❖ REM sleep is the last stage of sleep where your brain is very busy and your eyes move quickly.
- ❖ REM sleep is where you dream and your muscles are still
- ❖ There are usually spells of 3-5 REM every night. This is when we deal with our emotions and stress and also remember memories.
- ❖ The idea is that during one night of sleep we have a good mixture of these different stages of sleep. This will help us feel awake in the morning.
- ❖ Sometimes when we are stressed and worry too much for too long, our brain does not slow down and we do not get the 'deep' sleep stage. This means we don't recharge our batteries fully and we wake up tired.

Do	DON'T
Have a warm milky drink before bed (milk, Ovaltine, Horlicks)	Avoid too many drinks with caffeine in them (e.g. coffee, tea, cola). Avoid them at all 6-8 hours before bed
Have a lavender or camomile tea before bed	Avoid drinking alcohol – it may help you to fall asleep, but it disrupts the sleep itself, wakes you up often and causes you to not feel rested after sleeping
Eat a light meal earlier	Avoid heavy, rich and spicy evening meals Avoid having cheese as it's known to give you nightmares
Reduce the amount of noise and light that comes into the bedroom as much as you can	Avoid smoking just before going to bed
Have a long, hot bath before going to bed Lavender bath products or scented candles are especially good as they can help you relax	Avoid exercising up to 2 hours before bedtime
Relax by: meditation, reading a book, imagery exercises (see the relaxation section of this workbook), muscle relaxation etc.	Avoid staying up late chatting with friends either in person, online or on the phone
Listen to some relaxing music or radio Possible relaxing radio stations include: ClassicFM (99.9-101.9 FM) – classical music Radio 4 (92-95 FM) – relaxing chat Magic (105.4 FM) – relaxing contemporary music	Avoid screen time before going to bed
Make sure that your room is cool but not cold (usually recommended between 15.5-20°C)	Make sure that your room is a comfortable temperature. Avoid having the heat up too high or down too low in your room
Only go to bed when you are really tired and your eyes feel heavy	Avoid staying in bed awake for longer than 15 minutes If you're lying in bed awake, get up, briefly do something (e.g. go to the bathroom) then go back to bed and try again
Remove your clock from the room or turn it away	Avoid checking the time during the night as it may make you feel more anxious and keep you awake
Use your bed for sleeping	Avoid spending the day in bed and using it as a place for other activities like watching daytime TV
Try to stay awake during the day - Being outdoors for 30 mins has been shown to give you a better quality of sleep - Going for a short walk during the day when you are sleepy will help you to feel more awake	Avoid napping during the day

Nightmares

Nightmares usually happen during REM sleep. This is when we have vivid dreams. When you wake up from these nightmares, you may feel frightened, anxious, scared or sad. You may also wake up sweating and you may feel your heart beating really quickly.

Because nightmares can be very frightening you may begin to worry about going to sleep. You might try using medications or drinking alcohol to help you get to sleep.

You might also start:

- ❖ Staying up late
- ❖ Leaving the lights or the TV on at night
- ❖ Avoiding sleep as much as you can

Nightmares affect the quality of your sleep. They may stop you from falling asleep or staying asleep. Not getting enough sleep may affect your mood and cause you to feel anxious or irritable and even stressed.

How to deal with nightmares:

Grounding and Relaxation skills to try yourself:

- ❖ Grounding techniques are helpful to distract or distance you from the upset that nightmares can cause you, by getting you to focus on the present moment.
- ❖ First, be sure to completely wake up after having a nightmare. The idea is to help you get back to the here and now, and to help you feel safe before you go back to sleep (which you can't really do if you are drowsy or sleepy).

Tip: it is useful to have a nightlight or a lamp near your bedside to help you adjust to being in the present moment again.

It's all about your senses. Focus on:

- ❖ 5 things you can see
- ❖ 4 things you can feel
- ❖ 3 things you can hear
- ❖ 2 things you can smell
- ❖ 1 thing you can taste

If you need a little more help, you can do breathing exercises after you have done a grounding technique. Breathing exercises are in the first part of this workbook.

Improving Sleep: Goal Setting Sheet

Some people find planning to try one or two of the sleep techniques at a time helpful. You may wish to use the example planner below to help you try and stick to your plan. You can record how helpful you found each technique or create your own plan. Don't forget, there is more than one reason why people have a bad night's sleep, so don't give up on a sleep technique without giving it a number of go's!

Date of week to try new technique	TECHNIQUE	PLAN (To be completed by you)	RATING OUT OF 5 1=made it worse, 3=no change, 5=big difference
	Avoid caffeine / smoking 6-8 hours before bedtime	I will not have caffeine/a cigarette after ____pm.	
	Limit alcohol use	I will have no more than ____ drink(s) this evening.	
	Exercise regularly but not within 2 hours of bedtime (if able to do so safely)	I will ____ for ____ minutes at ____ (time) on the following days: _____	
	Make sure your bedroom is a comfortable temperature, quiet and dark with a good mattress and pillow.	I will make the following changes to my bedroom:_____	
	Take a hot bath 1-2 hours before bedtime	I will take a hot bath at____pm.	
	Have a warm milky drink and a biscuit/light snack before bed	I will drink a mug of_____and eat _____or _____ before bed	
	Avoid naps during the day	I will try not to nap. If I must I will limit it to____ minutes about 8 hours after I awake and will use an alarm to wake me.	
	Avoid clock watching	I will remove the clock from my room. If I need it for an alarm, I will turn the clock to face the wall or put it out of sight and reach.	
	Stay on a regular sleep routine	I will get up at____am, 7 days a week,no matter how poorly I slept that night.	

Managing Pain

Pain is one of the common symptoms that people who have Long Covid experience. Many people will have had some aches and pains before getting ill. Being unwell may have made these problems come back or get worse. This is because joints and muscles work better when we move them often, and when we are unwell, we are moving about less. This can cause aches and pain stiffness and muscle weakness. Muscle weakness can make it difficult to do things like standing, climbing stairs, gripping objects with your hands or lifting your arms above your head.

Pain can be in any area (joint pain, muscle pain, headaches, chest pain and tummy pain), or feel like it is all over your body. The most common areas to feel pain are your shoulders and back. Some people also have feelings such as numbness, pins and needles, and weakness in their arms or legs. Long-term pain (lasting for more than three months) can be disabling and can affect your sleep, tiredness, mood and how you are able to concentrate or work.



Don't worry the Pain Cycle can be broken.

You can work through mild pain, but don't push yourself too much. Trying too hard can make your pain worse and cause you tiredness. This is called PESE (post-exertional symptom exacerbation) which is described earlier in this workbook.

HOW CAN I MANAGE MY PAIN?

Pain can be helped in many ways. It is important you look at your whole lifestyle, not just medication.

Think about:

- ❖ Sleep habits: try to get enough restful sleep.
- ❖ Relaxation, meditation, listening to calm music you like.
- ❖ Choose activities that you enjoy for regular and gentle exercise
- ❖ Pacing: plan your day to space out activities and rest in between (see information on pacing earlier in the workbook)
- ❖ Nutrition: make sure you are eating well.
- ❖ Be kind to yourself: talk to yourself the way that you would talk to a friend or loved one!
- ❖ Work within your limits: don't push yourself into more pain.

General pain, joint or muscle pain can be managed by over-the-counter painkillers such as paracetamol or ibuprofen. Your GP or pharmacist can help if you need more help to control your pain. Sometimes it can be difficult to completely control your pain, but you can try to get it to a level that you are able to function better.

Brain Fog

Brain fog is not a medical term but it is used to describe a range of symptoms including:

- ❖ slowed down or 'fuzzy' thinking
- ❖ difficulty concentrating
- ❖ difficulty tolerating loud noises
- ❖ confusion
- ❖ slowed down problem solving
- ❖ struggling to find words
- ❖ difficulty controlling emotions

These symptoms can be worrying and might cause you anxiety. The good news is that people usually recover from brain fog.

It helps if you can understand what affects brain fog and what can make it worse:

- ❖ Fatigue
- ❖ Shortness of breath
- ❖ Post exertional symptom exacerbation (explained earlier in this workbook)
- ❖ Mood changes
- ❖ Pain

How can I help my brain fog?

Reduce distractions: This will help you focus on a task so you will use less time and less energy. Do things when you are less tired: Choose the best time of the day to do a certain task. If for example you are very tired in the mornings, change the time you make that phone call or task to the afternoon or evening.

Say things out loud: Sometimes if you repeat things or put your thoughts into words, it helps you to focus and remember them better.

Take small and often breaks. Take small breaks often throughout the day. It is important to rest your body and your mind. Try to use some of the mindfulness and relaxation techniques from earlier sections of this workbook to help you make the most of your small rest.

Set goals: SMART goals are discussed later in this workbook. Set your goals around your values and make sure you complete the most important tasks first. This will give you a clear 'to do' list.

One thing at a time: Do not put pressure on yourself. Remember that stress and worry can make brain fog worse. Recognise your limits and pay attention to what your body is telling you. Don't start too many tasks at once and don't overwhelm yourself.

Take your time: Rushing makes you use more energy and can lead to frustration and worry.

Aids: If you have any aids, use them. Use the tools and techniques you learned from this workbook to help you work through your tasks in an organised way.

Pacing: Refer to the pacing part of this workbook. If you don't pace what you do through the day you will eventually burn out. We know that being tired will make your brain fog worse, so pace your activities in order to avoid this.

Healthy eating: A regular and balanced diet will help your recovery and in turn make you less fatigued.

Sleeping well: Good sleep is important to make sure your body battery is charged at all times. Refer to the sleeping section of this workbook.

Writing things down: This will help you to organise your thoughts and reduce the pressure to remember everything.

Breathing control: Many patients with Long Covid have a breathing pattern disorder. This is discussed earlier in the workbook. A poor breathing pattern can lead to brain fog or even make it worse.



Work And Education

What is work?

Work can be paid employment (either self-employed or employed by a company), or something you do on a voluntary basis. Voluntary work can include looking after children or a loved one regularly or working for a local charity. You might be retired, but still take part in community activities, or you might be a student going to school, college or university.

Employment, work or education can be meaningful and important in different ways. Work can be a way of making money, but it can also be something that gives you enjoyment, pride, and it can make you feel good about yourself. Not being in work, or not being able to manage at work for whatever reason, can be scary.

This section will focus on getting you back to paid work, but it should also be useful if you go to school, college or university, or if you volunteer.

What to do while you are off work:

While you are off work there are a few things you need to do:

- ❖ Keep in touch with your employer and/or line manager.
- ❖ Find out about your workplace sickness absence policy.
- ❖ Know what your rights and responsibilities are about staying in contact with your line manager.
- ❖ Speak to your employer about what sickness benefits you may be able to get.
- ❖ Ask your employer if you will still be getting paid in full, or just getting Statutory Sick Pay (SSP).
- ❖ Speak to your line manager about being referred to occupational health (if your workplace has one).

If you are getting Statutory Sick Pay, it is useful to ask your employer and/or line manager how long this will last for. For more information about other benefits or to get advice about income maximisation, please visit the following website: <https://www.gov.uk/browse/benefits>

What to do when you feel ready to go back to work:

- ❖ If you are off for 7 or less days you can self-certify for this period (you might need to fill in a form).
- ❖ If you have been off for more than 7 days, you will need to get a fit note from your healthcare professional, usually your GP. For more information, please visit: <https://www.gov.uk/taking-sick-leave>
- ❖ Speak to your employer and/or line manager before you go back to work to plan your return.
- ❖ Make a plan (if possible) of what you will be expected to do when you return to work.
- ❖ Remember all your coping strategies in your tool box and use them when you need them.

Returning to work with Long Covid

People with Long Covid have found a number of common problems they can have at work.

These include difficulties with:

- ❖ Fatigue
- ❖ Breathlessness
- ❖ Brain fog
- ❖ Feeling emotional
- ❖ Anxiety
- ❖ Pain
- ❖ Concentrating on tasks
- ❖ Following a conversation
- ❖ Multi-tasking
- ❖ Headaches

You may have noticed some of these changes, and you might be worried about how they will affect how you will manage to do your job.

If you have a health condition, such as Long Covid, that has lasted, or is likely to last for 12 months or more and this is affecting your day-to-day activities, The Equality Act (2010) will be able to help you. The Equality Act (2010) states that your employer must look at reasonable ways that your job could be changed to help you to return to work.

This is why it is important to stay in contact with your employer and/or line manager to help you prepare and plan for going back to work. This will make going back to work as supported as possible for you.

Let's now think about the job that you do. Think about the following questions and write your answers down here:

What is your role? What are the main things that you do when you are at work?

What are you looking forward to? What are you confident about doing when you go back to work?

What are you worried about? What do you think might be challenging about going back to work?

What support do you already have in place that will help you return to work successfully?

What changes do you think might be needed?

What more do you think your employer/manager/colleagues could do to help you?

What can you/your family/support network do to help you to return to work successfully?

Having Long Covid may have changed how, when and where you are able to work. This is why it is so important to keep in touch with your employer/line manager to discuss how you are feeling, how you are dealing with this, and how you can return to work.

Reasonable Adjustments

Reasonable adjustments are changes that can be made for you to make it easier for you to work. What might reasonable adjustments at work look like for you?

- ❖ An extended phased return to work – this might be a gradual increase in work duties or hours
- ❖ Altered hours – this might be changes to the time or length of time that you are at work
- ❖ Amended duties – this might be changing what you do while you are at work to make sure it is things that you can manage
- ❖ Workplace adaptation – this may include changing things around your workplace to make it easier for you, or perhaps suggesting that you work from home

Normally, phased return to work is a way of helping you to return to full-time work, usually over a period of 4 – 6 weeks. You would normally gradually increase the amount of work you do each week over this time.

If you have been off work for a long time with Long Covid, an extended phased return to work is likely to be the best for you. The goal of an extended phased return is to allow you to slowly increase your work duties over time, without making your symptoms worse.

If your return to work is making you feel worse, or you begin to struggle with your health, speak to your GP and line manager/HR representative to explore other options.

Here are some of the most common difficulties that people with Long Covid might have at work and things that can be done to help:

WORK CHALLENGE	WHAT MIGHT HELP
Brain Fog	<ul style="list-style-type: none"> ❖ Give information in different ways e.g. visually and verbally. For example, instead of simply telling your employee what to do, also give them written instructions ❖ Allow use of memory aids. For example, encourage the use of checklists, notes, calendars and phone reminders
Fatigue and Reduced speed of work	<ul style="list-style-type: none"> ❖ Give the employee extra time to meet deadlines ❖ Allow them to take more breaks as needed ❖ Allow flexible working hours
Reduced attention or becoming easily distracted	<ul style="list-style-type: none"> ❖ Highlight important information with the use of colours and illustrations ❖ Allow the employee to work in a less distracting office or area (perhaps at home) ❖ Clear desk clutter, leaving only items needed to complete the task ❖ Reduce noise in the workplace and adjust lighting as needed
Loss of confidence or anxiety about performance	<ul style="list-style-type: none"> ❖ Regular planned 1:1s with line manager to provide feedback, discuss issues and find solutions to problems ❖ Buddy system

Remember that **YOU** are the most important part of this conversation – if you feel that things are not working for you when you start back at work, let your GP and your employer, supervisor or human resources know as soon as possible. This will let you discuss what you feel is going well and what might need to be changed so that you can stay at work.

Earlier in this workbook we looked at Pacing and Energy Conservation (ways to save energy) and you used an Activity Diary to plan your day. It is useful for you to now look at those sections again and think about how work will fit into your daily routine.

Would you be happy to return to work with a pattern like this?

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Day	Work	Work	Work	Work	Work	Crash	Crash
Night	Crash	Crash	Crash	Crash	Crash	Crash	Crash

This is the same as the 'Boom and Bust' cycle that we spoke about in the Fatigue Section. Not giving yourself enough time to rest and recover during the day means that you push yourself too hard and have to recover where you can in the evening.

Think about how you can spread your work more flexibly, breaking up your schedule and introducing breaks and protecting your leisure and sleep times. It helps to think about what a normal day might look like. You can use what you have learned about Pacing and Energy Conservation to help you organise your day.

Think about things like travelling to and from work – what will this look like? Will you be driving? Will you be taking the bus or train? Do you have problems sleeping? If you wake up and don't feel refreshed, will this affect the rest of your day?

When you are making the decision and setting a date to go back to work, you need to give yourself time to match your activity to test your new routine. Things to consider planning into your day are:

- ❖ Getting up and going to bed closer to usual work times
- ❖ Getting back into familiar routines e.g. showering and getting dressed
- ❖ Having meals at the times you normally would if you were at work
- ❖ Include more activities that challenge your brain – e.g. checking emails
- ❖ Think about who will help you at home so you can rest, get to work on time, take kids to school, do the housework, shopping etc.
- ❖ Setting aside time to rest and relax

This will help you understand if you are ready to return, or if you need to reconsider the reasonable adjustments required to support you.

IF YOU ARE WORKING FROM HOME:

Working from home is something you might want to think about when you are planning how you will go back to work. If you are doing this, it is important that you carry out a self-assessment of your work station.

This means looking carefully at things like your desk, computer, mouse, chair to make sure that you have the right equipment to carry out your job safely. Your employer must make sure that your workstation meets the Health and Safety Executive (HSE) guidelines if you are going to be working from home for a long time. For further information on this, please visit: Home working – your health and safety responsibilities <https://www.hse.gov.uk/>

For some people, working from home is easy. For others, it is more difficult. Here are few things you may want to try to make sure you make the most out of working from home:

- ❖ Get dressed and ready as if you are going into your usual place of work
- ❖ Think about your routine and stick to it – have clear starting and finishing times, clear times for breaks. Aim to take breaks away from where you are working
- ❖ Think about taking your lunchbreak outside, if the weather is nice enough
- ❖ Try to break up your day by having some meetings and phone calls throughout the day
- ❖ Try to use video calls for meetings as it will give you some face to face contact
- ❖ Try some gentle stretching and movement exercises if you are working at a desk most of the day
- ❖ If it is possible, set up your place of work / desk away from your leisure spaces (e.g. living room, bedroom). Try to put your laptop away or cover it up so you are not tempted to return to your desk after work

More information about how to set up your home workstation can be found here: <https://www.posturite.co.uk/help-and-advice/advice-sheets>

Access to Work is part of the Department for Work and Pensions (DWP). It can give funding for things that you are having difficulties with at work because of your Long Covid. You do not have to pay the money back, and it can be used to help you in lots of ways, such as:

- ❖ Travelling to work
- ❖ Equipment, or making changes to things that you use in your work
- ❖ Support to carry out tasks that you cannot do as part of your job

You can find out more information and apply to Access to Work here: <https://www.gov.uk/access-to-work><https://www.gov.uk/access-to-work>.

EXTRA INFORMATION

Allied Health Professionals (AHPs) include different health professionals such as: Dieticians, Occupational Therapists, Physiotherapists and Speech & Language Therapists. We use our skills to help you to be as independent as you can be. This will let you manage your health condition, and either go back to what you were doing before or start something new. This might be a job, training, learning or doing something different.

The AHP Health and Work Report is a form that can be used to keep a note of advice and recommendations that are made for you. It can be useful for you, your GP and your employer to help you get the right support when you return to work.

Welfare Rights services in the NHS can give you free, expert advice on any benefits you may be entitled to, and any problems you might be having with debt. This is a confidential service, which means we will not speak to anyone else about it.

ACAS (Advisory, Conciliation and Arbitration Service) can give free advice and support to both you and your employer. Please visit www.acas.org.uk for more information or call: 0300 123 1100

You can get general advice and information about benefits from the Citizens Advice Bureau. Please visit <https://www.cas.org.uk/> or call: 0808 800 9060.

What's Next?

After finishing this workbook, you may be thinking – what now? This is a normal feeling, but remember, this is just one step on your self management journey.

This workbook has given you a lot of information and advice to help you understand your Long Covid, and to live well with Long Covid. By now you will now know that Long Covid recovery isn't about the quick fix, but how to manage your symptoms. There will be times when you feel your symptoms are getting worse, and times where you feel you are improving – this is all a part of the journey. You can continue to be flexible in your approach to self management of your symptoms.

If you are still struggling with managing your symptoms, or those symptoms change, please consult your GP or Healthcare Professional.

In future, please think about this workbook as your 'GO TO' for help and advice. Use it as a reminder of all the great work you have done and any improvements you may have made.

Use the following pages to guide how to think about what you have learned.

MY LONG COVID TOOLBOX



LOOKING BACK

What, where and why?

What have I gained from this workbook?

What am I going to change because of the things I have learned?

Can I do it all by myself or should I be asking someone else to help me? Who should I talk to?

Realistically, when can I achieve this by?

Actions

What are the first things I will do to achieve my goal?

-
-
-

Long term action plan

What will I do to make sure I stick to my plan?

-
-
-

SETTING GOALS

After going through this workbook, we think it is important that you know how to keep an eye on how you are doing, and how to make sure you know exactly what you are aiming for.

In healthcare we always aim to set SMART goals, both with people we work with, and for ourselves.

What is a SMART goal?

Specific	You're more likely to reach your goals if they are specific. For example – 'I want to be able to exercise' isn't very clear but 'I want to be able to get back to riding a bike' is easier to work towards.
Measurable	It is easier to know when you have reached a goal if it can be measured. Distance, a time limit or the number of times you do it are ways to measure goals; e.g. 'I want to be able to cycle 5 km with ease'.
Achievable	It is important to be honest with yourself and realistic. If you have never cycled in your life and you don't have a bike, maybe this goal will be too hard, and you are setting yourself up for a fail.
Rewarding	Every time you set yourself a goal and you reach it you have a certain feeling. It might be happiness, maybe relief or maybe sense of pride and progress. Make sure that the goals you set yourself give you that positive feeling and they mean something to you.
Timed	Set yourself a time to achieve your goal. Treat it more like a check date for the goal. You may change the time it will take to get there but at least you know how much time you have given yourself to check how close you are to reaching your goal.

So to sum up, if we take an example of cycling, what would the SMART goal look like? Have a go at setting yourself a SMART goal first and then compare it to this:

'In one month, I will be able to cycle 5km without stopping'.

Choose to set yourself goals about activities that mean something to you. They don't always have to be exercise or physical activity. It may be that what matters to you is actually being able to go out for dinner with your family or friends, or perhaps doing some gardening. Either way, make sure that your goals are important to you.

Make sure that you set yourself small steps and small actions to reach your goals. That way you can keep an eye on how you are getting on. However, if things change, don't feel guilty about changing the time you are giving yourself, or even changing your goals.

Keep track of your goals to remind yourself of what you are trying to reach. You might want to use the following form to help you do this.

Short Term Goal (Days)	Things I Can Do To Achieve It	Date Set	Date Completed

Long Term Goal (Weeks/Months)	Things I Can Do To Achieve It	Date Set	Date Completed

Resources

Useful Long Covid Resources

- ❖ <https://abscent.org/>
- ❖ <https://wellbeinghub.scot/covid-landing-page>
- ❖ <https://www.chss.org.uk/long-covid/>
- ❖ <https://www.chss.org.uk/documents/2022/05/life-with-long-covid-essential-guide.pdf>
- ❖ <https://www.longcovid.scot/>
- ❖ <https://www.mastcellaction.org/>
- ❖ <https://www.mind.org.uk/>
- ❖ <https://www.nhsinform.scot/Longcovid>
- ❖ <https://www.nice.org.uk/guidance/ng188>
- ❖ <https://www.potsuk.org/managingpots/>
- ❖ <https://www.sign.ac.uk/patient-and-public-involvement/patient-publications/long-covid/>
- ❖ <https://www.yourcovidrecovery.nhs.uk/>

Anxiety

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-anxiety>
- ❖ <https://wellbeinghub.scot/resource/top-tips-for-managing-anxiety/>

Breathlessness & Cough

- ❖ <https://breathingspace.scot/>
- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/about-long-covid/signs-and-symptoms-of-long-covid/>
- ❖ <https://www.chss.org.uk/documents/2022/08/managing-breathlessness-with-long-covid-2.pdf>

Cognition

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-brain-fog/>
- ❖ <https://www.nhsinform.scot/healthy-living/keeping-active/>
- ❖ <https://www.chss.org.uk/documents/2022/08/exercising-safely-with-long-covid.pdf>

Fatigue

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-fatigue/>
- ❖ <https://www.chss.org.uk/documents/2022/05/long-covid-fatigue-essential-guide.pdf>
- ❖ <https://wellbeinghub.scot/resource/exhaustion-fatigue/>
- ❖ <https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf>
- ❖ <https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy>

Nutrition and Hydration

- ❖ <https://www.nhsinform.scot/healthy-living/food-and-nutrition/>
- ❖ <https://wellbeinghub.scot/resource/juggling-eating-well/>

Sleep

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-sleep-problems/>
- ❖ <https://wellbeinghub.scot/resource/sleep-101-tips-on-how-to-improve-your-sleep/>

Physical Activity & Exercise

- ❖ <https://longcovid.physio/>
- ❖ <https://www.nhsinform.scot/healthy-living/keeping-active/>
- ❖ <https://www.chss.org.uk/documents/2022/08/exercising-safely-with-long-covid.pdf>
- ❖ <https://wellbeinghub.scot/resource/exercise/>
- ❖ <https://physiowinnipeg.com/blog/health-wellness/exercise-intensity/>

Pain Management

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-muscle-and-joint-pain/>
- ❖ <https://painassociation.co.uk/>

Emotional Impact of Long Covid

- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-low-mood-and-depression/>

For Children & Young People

- ❖ <https://www.longcovidkids.org/long-covid-kids-support-group>
- ❖ <https://library.nhs.uk/%20coronavirus-resources/children-and-%20young-people/>

Long Covid Media

- ❖ <https://www.chss.org.uk/long-covid/long-covid-me-podcast/>

Return to Work

- ❖ <https://www.healthyworkinglives.scot/workplace-guidance/illness-absence/Pages/employees-with-health-conditions.aspx>
- ❖ <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/about-long-covid/your-recovery/>
- ❖ <https://wellbeinghub.scot/resource/long-covid-graces-journey/>

Support Groups

- ❖ <https://covidaidcharity.org/>
- ❖ <http://www.dysautonomiainternational.org/>
- ❖ <https://www.longcovid.scot/support>
- ❖ <https://www.longcovidsupportscotland.com/>
- ❖ <https://www.potsuk.org/pots-uk-online-peer-support-groups/>
- ❖ <https://www.scottishopera.org.uk/join-in/breath-cycle/>
- ❖ <https://www.thistle.org.uk/>

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The information presented here does not replace the advice or counsel of a doctor or health care professional.

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If you need this information in another language or format, please speak to a member of your local team.

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