

A self-management handbook to support **your recovery from COVID-19**

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Who is this handbook for?



We know that recovery from COVID-19 can be a long and difficult process for some people. Both those that received hospital based care and people that were self-managed in the community report ongoing and often interfering symptoms. These symptoms can last for weeks or even months after you initially become unwell.

COVID-19 can affect people in very different ways. It can impact on many important areas of your physical, psychological, cognitive and social wellbeing. Symptoms that persist for weeks or months are now being referred to as Post-COVID syndrome or Long COVID.

This handbook has been created by a team of healthcare professionals who have many years of experience in working with people with a range of acute and chronic health conditions. These professionals also have direct experience in providing care to people living with the long term effects of COVID-19. The

guidance provided in this booklet is based on current knowledge, which is changing over time.

It is our hope that this handbook will support you and your family in understanding some of the wide ranging challenges you may experience post COVID-19. It will also offer you some helpful strategies and tips that will help you to cope more effectively with the challenges that COVID-19 poses to your body and mind.

It is important to remember that recovery from COVID-19 is very individual. Therefore, it is unhelpful to compare yourself to others. Instead it is much more helpful to focus on your own recovery and to set personal targets and goals that are realistic. This booklet is not a substitute to seeking appropriate professional advice and support. If you have any concerns or questions about how the topics covered in this booklet apply to you; then please discuss these with your healthcare team.

We hope that you find something that is helpful within this booklet and that it supports you with your recovery.

What is long COVID?

For some patients affected by COVID-19 the physical, psychological and cognitive symptoms will persist for many weeks or months after the acute infection. **Post COVID syndrome (also called PACS) or long COVID are the terms that are used when patients continue to feel unwell for more than 12 weeks after their Covid-19 infection.**

Although the pandemic is over, Covid remains in our communities and the long term consequences of this is still often overlooked. We know that it can cause significant suffering for both those affected and for their families.

There is still no internationally agreed upon diagnostic criteria. That is, that experts don't yet have enough evidence to agree on what makes up the diagnosis of long covid. Currently, most healthcare professionals internationally are using this "consensus" or agreed working definition:

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. A separate definition may be applicable for children.

*World Health Organisation
6th October, 2021*

Common Symptoms of long COVID

Symptoms of long COVID can be highly variable and people can also experience a wide range of symptoms – Over 200 have been reported. The most common are listed below:

Fatigue

Respiratory Symptoms,

- shortness of breath
- Cough

Gastrointestinal symptoms (digestive system)

- Abdominal pain
- Nausea
- Diarrhoea
- Change in appetite

Musculoskeletal symptoms

- Joint pain
- Muscle pain

Neurological Symptoms

Brain Fog

Headaches/Migraine

- POTS/dysautonomia

Psychological/psychiatric symptoms

- Symptoms of depression
- Symptoms of anxiety

Ear, nose and throat symptoms

- Tinnitus (ringing in the ears)
- Earache
- Sore throat
- Dizziness
- Loss of taste and/or smell

Dermatological symptoms

- Skin rashes

Poor Sleep

- Insomnia
- Sleep Apnoea

Cardiac (Heart) Symptoms

Palpitations

Tachycardia (fast heart rate)

What is the Post COVID clinic?

The COVID clinic was established in April 2020 with the original aim to provide specialist follow-up services for patients hospitalised with COVID-19 after hospital discharge. However, it soon became evident that there was a need to support patients who were never hospitalised with COVID-19 but suffered from persisting symptoms following their recovery, including those that had symptoms consistent with COVID-19 but were never tested due to restricted access to testing in the initial phase of the pandemic.



The COVID clinic accepts referrals from different sources, including GPs, Public Health, Occupational Health Departments and Hospital services. It is currently located in Carew House on the campus of St Vincent's University Hospital and runs every other Thursday (excluding public holidays). There is an additional virtual clinic on Mondays. The clinic offers medical review under the supervision of a specialist in Infectious Diseases, with links to other specialties, as clinically indicated.

What has the SVUH post COVID clinic taught us about long COVID?



It remains unclear exactly how many patients are affected with long COVID. Within the post COVID clinic, we have seen many patients who have symptoms for weeks or even months after their COVID-19 experience. We should note that we have also seen patients recover! The most common symptoms reported by patients attending the post COVID clinic at St. Vincent's University Hospital are fatigue, chest pain or tightness, shortness of breath, palpitations, poor concentration and/or "brain fog".

We know that these symptoms can affect a range of people, including those who are young and otherwise healthy. In our post COVID clinic, the average age of patients presenting is 47 years of age. However, people as young as 16 years of age have attended. Long COVID can affect people who were not very sick when they first got COVID. In fact, in our clinic, 75% of people with long COVID symptoms had a mild initial illness.

If you are experiencing ongoing symptoms post COVID, it is important to see your GP to make sure that there is no underlying cause for these symptoms, like include asthma, inflammation of the heart, or high blood pressure. Your GP may be able to determine if you need further tests or if onward referral to specialist services is needed. However, based on our experience so far, it is common for blood tests and other investigations to return as normal even if a person is experiencing ongoing symptoms.

At the COVID hub we are learning more everyday about the impact of COVID in the medium and long term. We are also learning about what can support and help patients. This booklet is aimed at people who are suffering from long COVID syndrome and hopes to help you manage symptoms and support you in your recovery.

Understanding self-management

The term “self-management” can be used to also mean many things such as self-care, self-regulation, patient education, or patient counselling. Self-management is more than just the practice of just providing information to the patient.

Self-management is a process through which patients actively cope with their recovery or chronic disease day-to-day as part of a daily routine.

Reach Out: If you are comfortable, you might want to talk to your family, partner, or close friends about your journey. Self-management is often most successful when there are good relationships among the patients and their health care professionals, friends and community, and family members. Family can be an important source of support for many patients. In studies, patients with higher levels of family support did better with their self-management.

Trial and Error: Most patients need to try out different self-management strategies to figure out which ones are most useful in their everyday life. This also allows them to figure out how to manage challenges in a way that is best for them.

Changing goals: Many patients with long Covid do get better, but this recovery can be slow and very frustrating. However, as you feel better, you may need to change your sleep, your physical activity, your mental health supports, or your diet.

Physical Recovery

The Role of Movement

For patients who have ever been in hospital or visited someone in hospital, you may notice that healthcare professionals put a lot of emphasis on getting patients out of bed as much as possible during their stay. That is because our human bodies were made to move, and when we are sedentary too long, this can cause new health problems and symptoms.

Even for patients with severe fatigue, we recommend sitting out of bed as much as possible and getting regularly getting some movement, like light stretching, to help prevent new joint pain/stiffness and loss of balance.

Here are some other ideas to help bring some movement into your recovery at home:

<https://www2.hse.ie/living-well/exercise/indoor-exercises/flexibility-exercises/>

These videos guide you through gentle stretches to maintain joint movement and balance. By using a video at home, you can choose to do as little as only 3 – 5 minutes and stop, unlike taking part in a whole class that you may not be ready for yet.

<https://www.hse.ie/eng/about/who/healthwellbeing/exercise-videos/chair-based-yoga-.html>

Chair Yoga can be an excellent way to start moving after illness. By using a video at home, you can choose to do just 3 – 5 minutes and stop, unlike taking part in a whole class that you may not be ready for yet.

<https://askthephysio.ie/resources/> are a series of booklets developed by Irish Chartered Physiotherapist for movement at home. This includes one specific for Covid.

Understanding the Role of Physical Activity in your Recovery

The role of physical activity in the recovery of Covid-19 is an area of active research in many centres, and recommendations may change. This section of the book is based on current evidence and best practice.

The majority of current evidence from multiple studies, including some data from physiotherapy-led programmes including here in Ireland, have shown that after 6 weeks of returning to movement *at their own pace*, many patients felt better and many were able to return to some of their activities of daily living. In these studies, all participating patients were screened prior to participation. Check with your doctor before returning to physical activity.

Physical Activity Basics

When you have been unwell with COVID you may have spent a lot of time in bed resting or sitting, especially if you were admitted to hospital. This period of reduced mobility can lead to joint stiffness, weakness, muscle tightness, feeling unsteady on the feet and reduced fitness.

Pacing:

When recovering from an illness most people experience ups and downs with their symptoms. Most people have a tendency to use their symptoms as a guide to how much they will do on a given day. This can result doing more on good days, to make up for bad days and can lead to one overdoing it. Overdoing things can lead to worsened symptoms and increased fatigue. This is over referred to as a “boom and bust” pattern of activity. It is important to remember that all the activities we do on a day-to-day basis require energy, whether these are physical, mental, emotional or social.

Pacing is about working in within your current capabilities or energy envelope and therefore avoiding overdoing it. By not overdoing things on good days it is possible to avoid the severity of symptoms on bad days. This can make it easier to predict the level of activity you will be able for.

Public health recommend at least 150 minutes of moderate intensity exercise per week for a person in the full of their health. It is important to try and slowly build up your exercise tolerance to meet these guidelines. Start low and go slow, even if you begin with walking 5 minutes a day. Once you’re comfortable walking 5 minutes regularly then build up to 10 and so on. Always be mindful of how you’re breathing feels and aim to go no higher than a 4 on your BORG breathlessness scale.

‘Little & often’ is a helpful mantra when you’re starting out. Do small distances but regularly to build up your stamina. Make sure to pay attention to the pacing advice we have outlined above.

The next section outlines some strengthening exercises that may be helpful to start as soon as you feel able.

There is a beginner/ intermediate & advanced level, choose which ones you do accordingly.

Start with 6-8 repetitions of each and build up to 10-12

If you have fatigue, only do what you can do without triggering your symptoms or rebound fatigue. If these exercise cause you pain or shortness of breath, stop.

Beginner Exercises



1. Knee Extension in Sitting

Sit in a sturdy chair with your feet supported on the floor. Bend your ankle and straighten your knee using the muscles at the front of your thigh. In a controlled manner, return to the starting position.

Repeat on each leg.



2. Heel Raises in Sitting

Bend and straighten your ankles in sitting as if you are going up on “tippy toes”.



3. Marching on the spot in sitting

Sitting in a chair, alternately lift your legs up as if you are marching on the spot.



4. Tricep Dip from Chair

Sit in a chair with bent elbows as shown. Straighten your elbows as if you are about to lift yourself up off the chair. Lift your bottom off about 1cm and then gently lower back down by bending your elbows

Intermediate Exercises



1. Wall Press Up

Stand in front of a wall with your hands in front of your shoulders and elbows straight. Do a press up by bending your elbows to bring your body close to the wall. Keep your hips and knees in line with your body.



2. Sit to Stand

Sit on a chair with your arms on the supports. Shift your weight forwards and stand up.



3. Heel Raise

Stand in front of a chair or counter and place your hands on it lightly for support. Push up on your tippy-toes.



4. Bicep Curl

Stand tall with your arms by your side and palms facing upwards. You can use a small weight or a water bottle. Bend your elbow to bring your palm towards your shoulder, then gently return to the starting position

Advanced Exercises



1. Step Up

Stand tall in front of a step. Place your whole foot on the step and step up. Keep your hip, knee and toes in line.

Repeat on each leg.



2. Chair Squat

Stand in front of a chair. Take a small step in front of the chair. Act as if you are going to sit down into the chair. Once your bottom touches the seat, immediately stand back up.



3. Wall Press Up

Stand in front of a wall with your hands in front of your shoulders and elbows straight. Do a press up by bending your elbows to bring your body close to the wall. Keep your hips and knees in line with your body. To make this more difficult, you can take a step back away from the wall.

The Role of Nutrition in Recovery

It is important to eat well to support your recovery from COVID-19. COVID-19 can cause fever, cough, fatigue, pain, difficulty breathing as well as changes in taste and smell. These symptoms can affect your appetite and ability to eat. This section of the booklet will:

- ✓ Give you ideas on how to meet your body's nutritional needs
 - ✓ Provide tips for eating well to manage any side-effects after COVID-19.
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1. Tips for eating well

General nutrition guidelines suggest a diet including vegetables, fruits, whole grains, healthy fats, fish, poultry, beans and eggs, dairy, and limited intake of pork/red meats. The 'Mediterranean Diet' has been shown in studies to be good for people with a variety of chronic disease.

- Plenty of whole grains (high-fibre breads, cereals, brown rice etc.).
- Fruit (2 or more portions) each day.
- Vegetables (4 or more portions) each day – whatever types you enjoy.
- Oils (especially monounsaturated oils like sunflower and olive oil). Use a small amount of these oils in cooking and salad dressings.
- Nuts and seeds – great to add to snacks and salads.

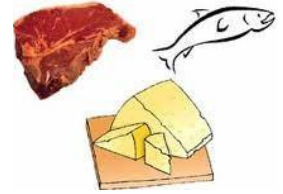
Include omega 3 fats and fish oils

There is insufficient evidence for the use of restrictive diets (e.g. low histamine diets, anti-inflammatory diets, intermittent fasting) in long covid.

1. **Don't skip meals.** Have 3 meals daily with nourishing snacks in between meals. Aim to eat small amounts often.

Protein foods are needed to help muscle strength and function. Loss of muscle mass can make fatigue worse. Aim to have a portion at each meal. Great sources include:

- Chicken or turkey
- Fish (salmon, sardines, trout, tuna and kippers)
- Eggs
- Beans, peas, lentils, or tofu
- Unsalted Nuts
- Cheese, Greek yoghurt, protein enriched milk



2. **Carbohydrate foods** are important as they provide you with the energy needed to help you recover. Examples of carbohydrates include bread, cereal, rice, pasta and potatoes. Choose whole-grain and complex carbohydrate options where possible to prevent blood sugar spikes that can make fatigue worse.
3. **Fruits and Vegetables** provide essential vitamins and minerals to support your immune system. Try to consume 5 portions of fruit and vegetables a day.
4. **Dairy foods** provide calcium for healthy bones and teeth. Examples include milk, yoghurt, cheese, cream and Fromage Frais.
5. **Vitamin D** for healthy bones and your immune system. If you are indoors most of the day or you are self-isolating due to COVID-19 you may not be getting enough sunlight. Many foods are fortified with extra vitamins and minerals. It is important to include dietary sources of vitamin D such as:
 - Fortified breakfast cereals
 - Milk (fortified milk has extra vitamin D added)
 - Fortified margarine
 - Oily fish such as sardines, pilchards, mackerel, herring, salmon and trout
 - Eggs

Check HSE guidelines for public health recommendations for Vitamin D supplements. <https://www2.hse.ie/conditions/vitamins-and-minerals/vitamin-d/>

6. **Hydration:** It is important to keep well hydrated. Dehydration causes tiredness, dizziness and constipation. Get plenty of fluids (water, fruit cordials, juice, milk) each day. As a general guide, aim for about 8 cups a day.

2. What if I am having problems eating at home?

You may experience some of the side-effects below due to COVID-19 that can affect your eating and drinking.

Problem	What can I do?
Poor appetite, fatigue, or feeling full quickly.	Don't wait until you feel hungry to eat – try to establish a regular meal pattern. Have three small meals and 3 snacks a day (little and often). Avoid drinking immediately before or during meals - have drinks half an hour beforehand or earlier, or at the end of a meal. You can also try nourishing drinks (like smoothies) or with a snack between meals. Limit intake of drinks with little nutritional value e.g. cup of soups, tea, coffee, carbonated drinks such as Cola. If you are feeling too tired or unwell to prepare meals- use frozen or pre-prepared meals. Check if a delivery service is available from your local supermarket.
POTS/post-viral dysautonomia	Abdominal bloating and other gut symptoms are common. Try to eat small meals, high in lean protein and whole grains/high fibre. Extra fluid can help. High Salt diets help some patients but always discuss with your doctor first before adding high levels of salt or salt supplements to your diet.
Short of breath	Eat smaller portions of energy and protein rich foods more frequently throughout the day. Choose softer, moist foods that are easier to chew and swallow. Take your time while eating meals or snacks. Ask for help to prepare your meals if possible; consider using short-cuts such as frozen chopped ingredients/vegetables.

Dry mouth	Try to drink six to eight cups of fluid each day (including nourishing fluids such as milky drinks or juices). Add sauces such as gravy, mayonnaise, salad cream and cheese sauce to foods, and choose moist dishes like stews. Suck sugar free sweets, ice-cubes, ice-lollies or chew gum to help saliva production. Rinse and gargle with water after using an inhaler to keep your mouth fresh. Some over-the-counter may also help. Speak to your registered pharmacist at your local chemist.
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Feeling unwell, social distancing and isolating can make it difficult to go shopping for the foods you need. Below are tips for getting the foods you need:

- Use meals on wheels services or home delivery services offering healthy pre-prepared meals, if possible.
- It's useful to have a good supply of nourishing foods in stock in case you cannot get to the shops. Include convenience foods in your weekly shop as these will last longer e.g.

Tinned/ Packet Foods:

- sardines, tuna, mackerel, salmon
- Baked beans
- A variety of tinned fruits and vegetables
- Soups and sauces

Dry Foods:

- Porridge oats, cereal bars, biscuits, crackers
- Pasta, rice
- Skimmed milk powder
- Packet soups and sauces

Frozen Foods:

- Fish or chicken
- potatoes
- Frozen vegetables
- Ready prepared meals can be a useful option

Note on Supplements:

There are no recommended diets, supplements, shakes, or vitamins to aid in the recovery of Covid-19. If you are concerned that you have a deficiency such as Iron, Folic Acid, or B12, talk to your doctor. Best resources for expert evidence-based information that you can trust on eating well while recovering from COVID-19 can be found at:

<https://www2.hse.ie/conditions/covid19/recovery/eating-well/>

<https://www.indi.ie/all-food-facts-and-fact-sheets.html>

Maintaining a Healthy Weight with Long Covid

Weight gain in long covid is not uncommon, and the reason for this is not fully understood. It may be due to a number of reasons, and like many other long covid symptoms, it may be slightly different for every patient. We know that this is frustrating for patients, and can make some symptoms, like joint pain, worse.

Some reasons for the weight gain in long covid may include:

- Decreased activity level due to pain or fatigue
- Irregular sleep (getting enough good quality sleep helps maintain a healthy weight)
- Side effects of certain medications
- Diet high in sugary, processed. or convenience foods due to being too tired to shop or prepare healthy meals
- Possible post-viral changes to metabolism or hormones, such as insulin resistance. This is an interesting area of research.
- For a small but important percentage of our patients, Covid and the Pandemic has triggered recurrence or worsening of eating disorders, including binge eating disorder. Free supports available at **BodyWhys.ie**.

Note: Some of our patients choose or prefer to attend for private nutritional assessment or advice, since this is often reimbursed through insurance. We strongly recommend all patients attend properly qualified dietitians. The qualifications required to practice as a dietitian in Ireland include CORU and INDI registration. Find a qualified dietitian: www.indi.ie.

The Role of Sleep in Recovery

People may have changes to their sleep quality and quantity following their COVID experience. In fact, you may have heard the term “Coronasomnia” – the change to sleep after covid infection. This refers to the common problem that people have describe finding it more difficult to go to sleep, waking up multiple times during the night and finding it very difficult to go back to sleep after their covid infection(s). For some people, they may be sleeping far more than usual as their body has an increased sleep requirement. Others may find themselves very sleepy throughout the day. This is an important area of ongoing research.

We know that any of these experiences can be a deeply frustrating and difficult to manage. We also know that our sleep is key to good physical and mental health.

What we’ve learned: The lack of sleep often makes other long covid symptoms worse, including fatigue, mood, and brain fog -- so we do not want to ignore this one and wait for it to get better on its own!

It may be helpful to bear in mind that it may well take some time to come back to your typical sleep pattern. There are several simple things you can do to support sleep:

Sleep Tips:

- Implement a good sleep routine. This means going to bed at roughly the same time each night and getting up at roughly the same time each day.
- As you recover, eliminate naps during the day. If they are required, these should be no longer than 20 minutes.
- If you don’t have increased sleep requirements or if the need for excessive periods of sleep has reduced then aim to have 7-8 hours sleep per night.
- Spend some time winding down before you go to sleep. This may include listening to or practicing some relaxation exercises, listening to calming music, having a bath or reading a book.
- Relaxed breathing exercises or Progressive Muscular Relaxation exercises can be helpful for this (such as: www.cntw.nhs.uk/resource-library/relaxation-techniques).

- Meditation may also be helpful, but can take practice. You can download a free app that can help “Insight Timer” available through your app store or <https://insighttimer.com/>
- Reduce your exposure to blue lights in the evening. This means turning off all electronic equipment (e.g., phone, computer, television) 60 minutes before you go to bed.
- Avoid tea, coffee, energy drinks, alcohol or large meals or spicy foods late in the evening. Some find drinking chamomile tea or a milky drink helpful.
- Ensure that your bedroom is a comfortable, calm, clean and cold environment. It may be helpful to ensure that noise and light is minimised. This includes lights from televisions and alarm clocks. Our aim is to create a sleep sanctuary in the bedroom and to only use the bedroom for sleep, sex or restful activities such as meditation or reading.
- Sleep is improved if we can take some exercise and have exposure day light. Do some gentle exercise, within your limits, if it is possible for you. It is most helpful to do this in the morning or early afternoon. Try not to exercise within three/four hours of going to bed.
- If you are tossing and turning in your bed for 20 minutes or more, it is best to get up and go into another room. Don’t do anything stimulating. Read a book or do something relaxing and when you are feeling sleepy return to your bed and try to go to sleep again.
- You cannot force yourself to go to sleep, so do not try. Simply allow yourself to be relaxed and quiet, and sleep will come to you.
- Some people who have experienced COVID-19 describe an increase in nightmares or vivid dreams that can be frightening in nature. When we go through a difficult or traumatic period it is common for these experiences to occur. If this is happening, you might find it helpful to talk to your friends or family about these experiences so they support you. It might also be helpful to have some objects to reorient you to your room when you wake up. For example, something you can smell or touch to remind you that you are safe and at home.
- There is no indication that supplements -- including magnesium, zinc, resveratrol, nitrate – improve quality or quantity of sleep.

- We do not recommend alternative treatments, such as acupuncture or reflexology, as treatment for chronic insomnia.

**Common patient question:
Why don't you just give me sleeping tablets?**

Sleeping tablets do not help patients with chronic insomnia or the type of insomnia that wakes you up in the middle of the night. They can also worsen symptoms such as brain fog in some patients.

What if that's not enough?

Insomnia (whether difficulty falling asleep or staying asleep or both) is chronic if it last more than 6 – 8 weeks.

The recognised gold standard treatment for insomnia is CBTi (or similar approaches). One way to think of it is that it helps re-train your brain to sleep.

If needed, we will refer you to the clinical psychologist attached to our clinic who can help. We also recommend that patients who prefer other options can work with their existing therapist or E.A.P.

Patients who prefer to go privately, we recommend the experts at either <https://www.insomniaclinic.ie/> or <https://www.sleeptherapy.ie/> who use strictly evidence-based approaches.

The Role of Reducing Harm in Recovery

1. **Avoid Alcohol Misuse.** Recent studies have found that many patients recovering from Covid-19 may misuse alcohol to help cope with symptoms. Alcohol misuse can worsen many symptoms, including anxiety and insomnia. Avoid alcohol. If you choose to drink, we recommend low-risk drinking. Low risk drinking levels are 11 standard drinks for women or 17 standard drinks for men. Avoid binge drinking (more than 6 standard drinks in one occasion); drinks should be spread out over the week. Have 2 to 3 alcohol-free days per week. One standard drink is a small glass of wine, ½ pint of beer, or one pub measure of spirits.
2. **Quit Smoking or Vaping.** Free resources and support, including free nicotine replacement therapy, is available through the HSE. Sign-up for free at [Quit.ie](https://quit.ie). If you need help additional help quitting smoking or vaping, ask your GP or your doctor at your next clinic appointment.
3. **Be savvy with media and social media.** Always remember that another patient's journey is not your journey. If you are in an online support group, you should be finding it a positive experience and supportive. If you find that it is making you anxious or angry, consider stepping away or muting the group for a period of time. Remember that many patients do recover from long covid. Be particularly skeptical of cures or treatments being marketed in media or patient groups. There is no accepted treatment for long covid, though there is active research ongoing both in Ireland and abroad. If you are interested in a clinical trial or treatment, do discuss it with your doctor. ***Never pay to be part of a clinical trial, or to find out about one. Ethical (approved) clinical trials will never ask you to pay.***
4. **Take Steps to Avoid possible Reinfection.** Reinfection with Covid-19 or infection with other respiratory viruses such as RSV or influenza ('flu) can worsen your long covid symptoms or delay your recovery. Make sure that if you are up-to-date with your flu and Covid vaccines, if you are due one. If you have any questions about vaccination, make sure to ask when you are in clinic. Follow current public health recommendations, including washing your hands. While there are no longer policies about wearing masks in healthcare settings and on public transport, we know from research that they are still an effective way of reducing your risk of infection and many of our patients continue to mask in certain environments.

How to Support your Psychological recovery

We know that it is common for people to experience a range of psychological and emotional difficulties following COVID-19. People may experience psychological difficulties whether or not they were in hospital.

The next section of the booklet will help to guide you in your psychological and emotional recovery post COVID. The purpose of this section is to:

- ✓ Understand the common emotional and psychological challenges associated with COVID
- ✓ Learn strategies and ways of coping with these challenges

While most people will naturally adjust over time, some people might experience longer lasting difficulties. If difficulties last longer than a few weeks it might be helpful to discuss particular challenges with your GP or your mental health team if you attend one. There is a Psychologist working with the post COVID clinic and your team will be happy to refer you to this service if your difficulties persist over time.

The Patient Lived Experience:

Many patients with PASC have reported the experience that they have been told that their symptoms are “all in their head” or due to anxiety/depression. This experience has often led to poor relationships between health professionals and patients.

We know there is a risk that patients may not talk about their mental health symptoms because they are worried that their doctors will blame all of the other long covid symptoms on mental health. However, we also know that if we don't include mental health, this can lead to poorer outcomes for patients.

We try to be supportive, open, and non-judgmental in our clinic. We want to reassure our patients that not all patients with long covid have mental health symptoms, *but depression, anxiety, and/or suicidal thoughts are common post covid symptoms in as many as 26% of long covid patients*

Anxiety

Anxiety is a common human experience and feeling anxious is perfectly appropriate in some situations. We know that being an inpatient in hospital or trying to manage ongoing symptoms by yourself at home can be an extremely frightening and difficult experience. Also, having medical uncertainty and ongoing symptoms that you don't understand or that limit how you function is very naturally worrying and anxiety provoking. Therefore, it is so important to remember that fear and anxiety are completely normal responses to significant and ongoing changes in your physical health.

Anxiety is our body's natural reaction to real or imagined stressful or frightening situations. It is commonly referred to as the "fight or flight" response. During the "fight or flight" response our body's automatic survival mechanism kicks in and prepares for action; either to fight danger or run away from it as fast as possible.

When we are in "Fight or Flight" mode our heart rate increases, we breathe faster, we might sweat, get "butterflies" in the stomach and we may also notice that our attention becomes narrowed and looks out for more potential danger.

These responses happen automatically and are designed to keep us safe. Anxiety is important and natural. If we didn't have anxiety we would probably be in some kind of accident very quickly.



Post COVID it is likely that you will feel more worried, anxious or panicky than usual. You might find yourself spending a lot of time thinking back over your illness experience, worrying about becoming unwell again, or worrying about the symptoms you are experiencing and the uncertainty around how long they might last for. Living with long COVID can also bring about various other issues of concern such as financial worries or worry about not being able to work or to do things that matter to you such as exercise.

Anxiety affects people in different way and it may be associated with racing thoughts, difficulty slowing your breathing down, concentration difficulties or trouble sleeping for example. If anxiety is persistent for you or affecting your life or relationships, it might be helpful to consider some support strategies to help with your anxiety management. Some helpful tips are listed below:

Anxiety Management Tips

- Understand that “fight or flight” is an evolutionary response. Remember it is not your fault and that it is natural to have increased levels of anxiety when you have been and are unwell.
- It may be helpful to monitor anxiety and to keep a note of how regularly it happens and what seems to trigger it or start it off. This will help you better understand your experience and to see if there are aspects of it you can take action on.
- We know long COVID experiences are very varied and individual. Try to get a good understanding of your medical condition. Ask your healthcare professional to talk you through the symptoms that might be cause for concern and what ones you do not need to worry about. This will help to reduce your “hypervigilance” or over focus on bodily sensations.
- We know that trying not to think about worries is likely to make them worse. Instead it can be helpful to schedule some “worry time”. This is a set amount of time 20-30 minutes where you allow yourself to think about your concerns. If worries come up outside this time, then simply note them down for your “worry time” and continue with what you were doing.
- When you are feeling stressed or anxious it can be important to use problem-solving techniques to identify solutions. This can allow you to see aspects of your situation that are inside or outside your control and can help to make the challenges you are facing feel more manageable.
- When we are anxious we breathe more quickly and when we are relaxed we breathe more slowly. Relaxation and breathing exercises can make us feel safer and our body more relaxed. Remember, relaxed breathing is slower and deeper than normal breathing and it happens lower in the body in the belly or diaphragm as opposed to the chest area (see the Physical recovery section for more tips on breathing).
- Mindfulness meditation teaches us the skill of being in the present moment. Engaging with short mindfulness exercises might be helpful for some people particularly if you find yourself caught up in the past or future much of the time. Some people do not find this helpful.

Low Mood

Recovery from COVID can feel like an uphill journey or like a game of snakes and ladders. People describe periods of improvement followed by recurrence of symptoms. A long COVID experience can affect your identity and the multiple roles you hold in your life.

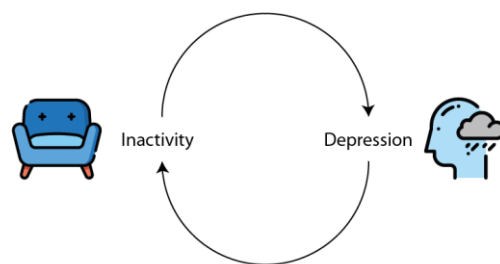


For some people, a long COVID experience might mean not being able to attend work and for most it will require significant adaptations to how life is typically lived. This will not only have an effect on you, but also on the important people in your life. Many people describe strained relationships with friends or family as a result of their changed health. Given this, it is perfectly understandable and natural for your mood to be lower than usual or for you to be more up and down on a day to day or week to week basis.

When our mood is low it is common to feel sad and hopeless, to be more tearful than usual, to lose interest in activities we usually enjoy and to have more frequent thoughts about death and dying. As well as this, there are also some common physical changes that are related to low mood such as changes in sleep pattern and energy levels, changes to our appetite and to our sex drive.

Having ongoing physical symptoms that limit your day to day activities, such as fatigue, is exceptionally difficult, and can change how you see yourself. You may not be as physically able to do the things that nourish you and bring you joy. Your body may look different with weight gain/loss as well as changes to the skin and hair for some. These sudden, multiple losses and changes can lead to a more negative thinking style which can further impact on how we feel and what we do.

Often a vicious cycle can emerge between physical limitations and mood, and vice versa. For example, ongoing challenges with fatigue and little change in energy levels over time may lead to thoughts about change being a hopeless pursuit and to feelings of isolation and loneliness. This in turn can lead to less motivation and to avoidance of engaging with physical activity, which in turn will reduce energy levels.



If you are low in mood there are many helpful steps you can take even when your energy remains low and you are less active:

Tips for Managing low mood

- Keep to a daily routine. Set up a daily routine for sleeping, eating and activity and try to stick to it as best you can.
- Do some exercise within your own limitations or energy envelope and get some fresh air each day.
- Try to do at least one thing per day that brings you a sense of pleasure or achievement. It is important for your available energy to be spent on things you need to do as well as what you enjoy doing.
- Don't wait until you feel like doing things. When our mood is low it can be incredibly difficult to access our motivation or drive system. Instead plan to do something each day whether you feel like it or not. Do first and wait for the feeling to follow.
- Discuss how you feel with your family and friends. We know that naming and sharing your emotional experience can lead to less distress and increased connection, which boosts moods.
- Try to avoid adding layers to an already difficult experience by being harsh and criticising yourself. Try to practice talking to yourself as you would a good friend.

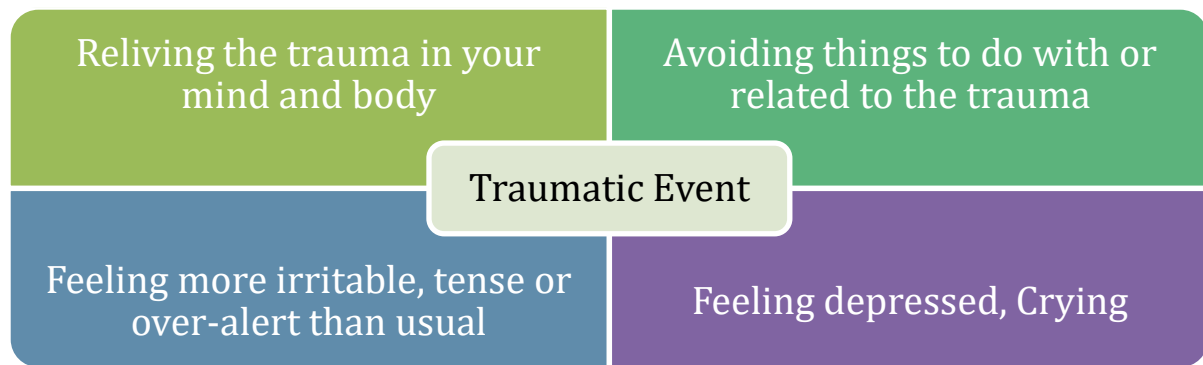
- People have very individual experiences of long COVID, so it is best not to compare yourself to other people who are in their recovery journey or to compare yourself to what you used to be able to do.

Adjustment and Trauma

A traumatic incident can be anything that is out of the ordinary range of daily events and this is deeply distressing to a person. COVID and its treatment created a number of traumatic experiences for many people. For instance, we know that some people had very distressing hospitalisation experiences and required admission to ICU. Many people nearly died or they thought they were going to die. Being in hospital was made more difficult by the many infection control measures in place, such as staff wearing personal protective equipment and by patients being in isolation and not having family and friends present. We also know that people managed their symptoms in the community and may have had very traumatic individual or family experiences at home.

It is common for people to be surprised by how they coped in and after a traumatic event. Traumatic events can really shatter the beliefs we have about ourselves, our lives and our futures. For example, contracting and becoming very unwell with COVID-19 may lead us to question beliefs we held that life is predictable or that we are in control over the future.

Following a traumatic incident, our minds and bodies do their best to protect us from experiencing the trauma again. They do this by holding on to the memory of the trauma very strongly to make sure that we do not experience it again. People have very different reactions to traumatic events. Some people will have mild adjustment challenges and recover naturally over time, while others will experience more severe and enduring reactions that are distressing to them. The following are some very common reactions after a traumatic event:



Post-traumatic stress reactions are normal and expected and not an indicator that you are “cracking up” or “going crazy”. These reactions can affect you in at least four different ways. They can affect how you **think**, how you **feel**, how you **behave** and the way your **body** works. For most people, these responses gradually reduce over time and the following tips might be helpful:

Tips for Supporting Adjustment

1. Experiencing images and flashbacks of traumatic events is your brain's way of trying to make sense of your experience.
2. Having an understanding of the four main experiences people often have after a traumatic event is important.
3. It makes complete sense to try to prevent distressing thoughts or images from coming to your mind. You might try to avoid thoughts, images or reminders. However, we know that trying not to think about something often has completely the opposite effect and avoidance and pushing thoughts away makes them worse.
4. It is helpful to think about and make sense of the trauma. You can do this by talking to friends, family and your medical team.
5. Some people find it helpful to write down information about their experience or about their nightmares. This may be scary and difficult at first but this can be helpful for some people to process what has happened.
6. If you have distressing images remind yourself that you are safe now and it may be helpful to come back to the here and now. You can use grounding techniques to help you with this. (See the end of this booklet for some examples of grounding techniques).

7. It is normal to feel overwhelmed. Get to know your own individual early warning signs and try different strategies to learn how to manage them (e.g., relaxation, short mindfulness practice).
8. Try to remember that you are not to blame for your illness or symptoms
9. Practice becoming more kind and understanding towards yourself when you are experiencing difficult emotion

If it has been longer than 4 weeks and trauma symptoms are still distressing and interfering for you then you may benefit from talking therapy. Up to 75% of patient may experience new anxiety and depression Post-Covid, and many need additional support. Discuss this with your healthcare team and they can refer you to an appropriate service. However, you can also self-refer for many options, many of which are free:

1. Start by talking to your own GP who may be able to refer you to Counseling in Primary Care Service (CIPC). You can read more about this service on the HSE website.
 2. You may be entitled to the **Employee Assistance Programme (E.A.P)** through your employer. E.A.P. is a confidential independent service. It supports employees with psychosocial issues, whether they are personal or work-related or whether they are affecting your job performance or your home life. You refer yourself. It is FREE. It is completely confidential (*neither your employer or your Occupational Health will be notified that you have used the service*).
- **MyMind.org** MyMind is community-based mental health services that work towards giving every person in Ireland equal access to mental health support early, affordably, directly, without stigma or delay. They offer reduced rate and affordable counselling services for eligible patients. For more information and to book an appointment, go to: <https://www.mymind.org>.
 - **Turn2Me.ie:** Most of our patients are eligible for MyMind.org. If you are not, you can register online for 6 **FREE** sessions of counselling through Turn2Me.ie.
 - **Private Insurance:** Many private insurance plans cover or reimburse at least 6 sessions of counselling. Patients are often unaware of this, so if you have private insurance, it is worth checking your policy.

Cognitive Recovery

It is very common for people to experience new difficulties with attention, memory and thinking clearly after having COVID-19. People may experience these difficulties whether or not they were in hospital. While the experience of “brain fog” is common in long covid, it is experienced differently by each patient.

The next section of the booklet will help to guide you in your cognitive recovery post COVID-19. The purpose of this section is to:

- ✓ Understand the common cognitive difficulties associated with COVID-19
- ✓ Learn strategies and ways of coping with these difficulties

Delirium

If you were hospitalised and particularly if you required intensive care you may have experienced something called delirium. Delirium is a medical term which means a severe state of confusion. Delirium can be caused by a number of factors such as the amount of oxygen your brain receives, the medications you are taking, infection, or if you have severe pain for example.

When a person is experiencing delirium they often cannot think clearly and coherently and feel confused. They might see or hear things that are not there even though they seem very real. They may have great difficulty understanding what is going on or they might believe unusual things. It is common for people to have very strong emotions such as feeling frightened or lonely or angry. Fortunately, we know that delirium is only temporary and it passes when the underlying cause is treated.

After discharge, some people might re-experience the images they saw in hospital. They might get flashbacks to things that didn't happen and find it hard to separate real events of their admission from events that didn't happen but felt real due to their delirium experiences. If you are having these types of flashbacks and they are distressing to you it does not mean that you still have delirium, but it may mean you need intervention to help you cope with the traumatic experience you have been through.

As a starting point, discuss your concerns with your GP or the post COVID team and they will be able to direct you to appropriate support options. Some of the suggestions outlined in the adjustment and trauma section above may also be helpful for you

Brain Fog and Cognitive Fatigue



Many people with long COVID are troubled by a variety of cognitive or thinking difficulties which are now being referred to under the umbrella term “brain fog”. This term describes varied problems with concentration, processing information, short-term memory or “thinking straight”. Cognitive

difficulties seem to be an issue for people that had severe illness and required hospitalisation. Some of these people may have had neurological events. But we also know that people who had mild illness and whom were managed in the community are reporting problems with their thinking and concentration too.

We know that people experience different levels and types of ‘Brain Fog’. For some people the effects can be mild and for others they can be severe. Brain fog has been described as being like a cloud or fog hanging over you which makes it difficult to think clearly. People often describe being forgetful, confused, unable to focus or concentrate, being mentally tired, or being unable to remember the correct words or being able to think quickly or take in large amounts of information.

It is important to note that for some patients, the symptom of brain fog may be made worse by:

- Poor sleep
- Anxiety, depression, stress, trauma/PTSD
- Physical fatigue
- Endocrine abnormalities: low thyroid, new diabetes, recent onset of menopause
- Autoimmune disorders
- Autonomic dysfunction, including POTS and dysfunctional breathing

Looking after these other conditions may help improve brain fog.

Cognitive Fatigue

Many people have experience of physical fatigue to some extent in their lives before COVID-19. For example following other illnesses or significant exercise. Mental or cognitive fatigue can be a newer and for some worrying experience with long COVID.

People describe cognitive fatigue in many ways, including feeling like their brain is 'shutting down' or 'running out of battery' after concentrating for a period of time. When you are experiencing cognitive fatigue, it can feel like you are no longer able to take in information or react to conversations or process what is happening around you.

Memory

Generally, people are reporting difficulties with their short term memory. If your memory is affected you might find it difficult to recall your illness experience. You also might find it challenging to hold new information in mind or you might struggle to remember previously known information such as dates or names. People can feel anxious if they are experiencing difficulties with their memory, particularly if this is a new experience for them.

Attention and Concentration

Many people are reporting problems with attention or concentration. People are reporting finding it hard to focus their attention for periods of time and can be much more easily distracted by background noise. This has made things like engaging with tasks for long periods of time difficult. You may also find that it is much more challenging to do two or more things at once.

Executive Functions

This refers to the mental processes that allow us to solve problems, make decisions, plan ahead and see tasks through to completion. For example, this skill is needed to book a holiday or to get the car fixed. Problems with executive functioning mean that people find it difficult to get going on tasks and to see tasks through. They may seem disorganised, impulsive and as though they are not thinking things through. In some instances people may find it difficult to monitor their behaviour.

We do not yet know the long term impact of COVID-19 on our cognitive or thinking skills. Some people with COVID-19 report their Brain Fog and concentration difficulties as gradually improving over time, while others report it as being a significant and ongoing challenge for them. We know that brain fog can be impacted by many of the other psychological difficulties discussed previously in this booklet. For example, our level of fatigue and low mood may impact on our ability to concentrate and attend to information even when you think it's important. If you cannot concentrate on something, it will be much harder to remember it. Also, if you are feeling very anxious about your memory or attention difficulties, this may in turn, make it more difficult to concentrate.

Therefore, it is important to remember that we can support our cognitive health in a broad variety of ways. This will include maintaining good physical and psychological health as well as using some of the strategies below:

- The first step to managing problems with memory and thinking is to acknowledge that you are experiencing them. These difficulties may not be lasting but acknowledging them will give you the best chance of managing them.
- Brain fog and cognitive difficulties are common after Covid-19. Take care to be understanding and kind to yourself as you continue to recover from COVID infection. Monitor how your mood and self-talk might be playing a part in your experience of cognitive difficulties.
- It may be helpful to discuss these challenges with your family and friends so they can support you and so you can come up with helpful coping strategies together.
- Try out using aids to support memory and planning. For example, use post-it notes, diaries, calendars and make to do lists. It may also be helpful to use alarms and reminders in your phone. Some people like to use noticeboards.
- Make sure you use any aids you require, such as glasses or hearing aids.
- Allow yourself extra time to complete tasks and plan regular breaks before and after tasks that you know are likely to require a lot of concentration
- Do one thing at a time and try to avoid multitasking.
- Limit distractions when you are trying to focus on a task or use gentle instrumental playlists that help with focus and concentration.
- Make a clear plan before approaching any new or complicated programme. Break down the activity into individual steps to avoid feeling overwhelmed.
- Keep a regular routine of physical exercise, rest, good nutrition, hydration as well as supporting your mood will impact on your cognitive functioning. See previous chapters for helpful tips and recommendations.
- Some people like to do activities for cognitive stimulation such as new hobbies or activities, puzzles, word and number games or reading. It is important to choose tasks that are achievable and enjoyable and to gradually increase difficulty over time. This will help with motivation and

feeling a sense of mastery or achievement. If you are not enjoying doing these activities, it might be best to stop and try something else.

Other Tips for Attention and Memory

- Keep important things in the **same place**. For example, store your car keys in the same drawer. Encourage your family members to also keep things in the same place.
- Try to follow a **daily routine** to do things so you will have less to remember.
- It is important to use **one efficient management system** rather than using multiple diaries/calendars
- Get in the habit of **checking your diary regularly**. Perhaps, first thing in the morning and just before you go to bed.
- If you fail to remember something, try to **remain calm**. It's normal to feel frustrated when you can't remember something, but when you are feeling like this; you are less likely to be able to problem-solve. Take a few minutes to calm down to help your memory to clear. Try slow, deep breathing or other relaxation exercises.
- Turn off distracting devices when needing to concentrate
- Ask people to repeat information or simplify what they are saying if you are feeling overwhelmed
- Write things down as this allows you to re-process information.
- Carry a notebook or diary with you if this would help and use it regularly
- Plan ahead as much as possible and give yourself time when making decisions. It's better to stop and calm down if you are flustered than to rush and make mistakes

If you feel your thinking, memory and concentration difficulties are lasting for several months after your COVID infection and are impacting on your ability to do your everyday activities, discuss your concerns with your GP or the post COVID team and they will be able to direct you to appropriate support options.

For patients with symptoms of “brain fog” and no other measurable cognitive problems, the current evidence suggests:

- **It is important to treat other symptoms such as pain, sleep problems, and depression/anxiety. These can make brain fog worse. In some cases, these other symptoms can slow your recovery from brain fog.**
- **Going through all of your medications with your doctor to make sure none of your medications may be making your brain fog worse.**
- **Just like patients who have physical fatigue, patients with cognitive/mental fatigue should be advised to begin an individualized return to activity programme**

- Physical movement 2 -3 times per week has been shown to help many long covid patients to improve cognition and sleep
- This does require frequent assessment of the impact of return to normal, daily activities - including school, work, and driving - is recommended to make sure symptoms do not flare and exercise is tolerated.

Does “Brain Training” Help?

We don’t know yet.

There is a current NIH research trial in the US called “RECOVER-NEURO” In this study, participants are regularly using an online brain training platform called “BrainHQ”.

There is good evidence that BrainHQ can improve cognitive function in people with brain injuries. This study, based in the US, wants to learn if improves brain function for people living with post-Covid symptoms.

This study is not yet complete, but if you would like to read more about it or to try brain training yourself using this platform, go to:

<https://www.brainhq.com/>

Symptom Management

In these next sections, we will talk about management of some of the most common post-covid symptoms.

Shortness of Breath

Many people with COVID-19 experience breathlessness. This often occurs when you are doing your normal daily activities such as using the stairs. However, it is important to note that while many post-Covid patients have breathlessness, there are different causes and types of breathlessness. It is not the same for every patient. Always talk to your own doctor about your breathlessness.

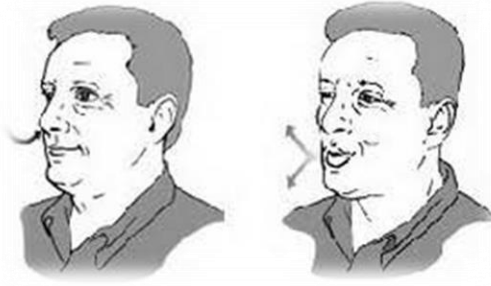
Feeling breathless can be scary and bring on feelings of panic and anxiety. This in turn can make your breathlessness worse.

If you are feeling breathless on exertion or while doing tasks the following techniques will help

1. **Pace yourself:** Only go at a speed that is comfortable for you, slow down to control your breathing
2. **Take rests:** If you are feeling very breathless stop your activity and use some of the breathing techniques below to recover. It is also helpful to try not to talk & exert yourself at the same time. Once recovered then carry on your task
3. **Relax or distract:** Try to focus on an object/picture/window view. Simply breathing in and out to a count of 3 seconds can help

Pursed Lip Breathing

- You may find this helpful if you are feeling panicked, or if you are having trouble slowing your breathing
- This technique encourages you to spend more time exhaling, which will make it easier to fill your lungs with air on the next inhale
- Practice in a position that is easy to breathe in. You may use one of the positions of ease shown overleaf. Breathe in gently through your nose, then breathe out in a relaxed manner through pursed lips. Keep your shoulders relaxed. Continue this technique until you feel that your breathing pattern is back to normal

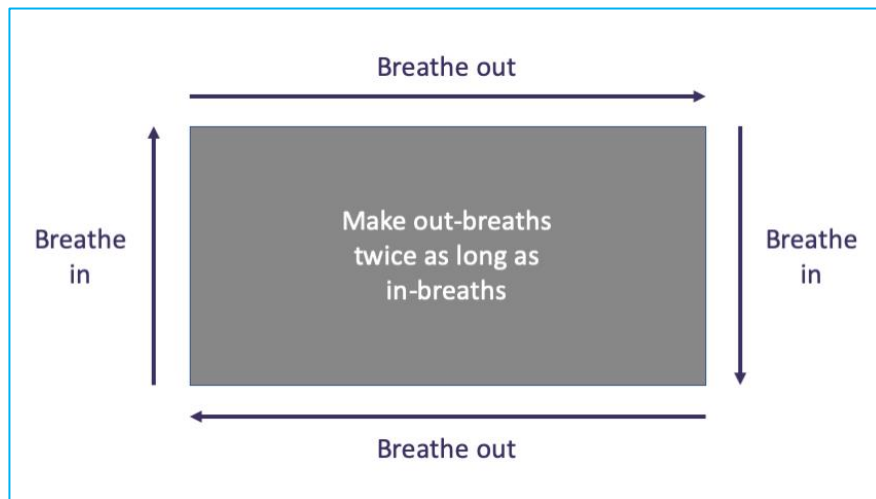


Relaxed Tummy Breathing

- The diaphragm is most efficient muscle that powers our breathing. Often when we are breathless the diaphragm is not being used to its full potential. This technique can help you to use your diaphragm more when you are breathing
- It's important to note that tummy breathing is not how we naturally breathe. You should practice this when you are not breathless to master the technique
- Practice in a comfortable position, ideally sitting up or standing. Your shoulders and upper chest should be relaxed. Place one hand on your tummy, feel the tummy rise and expand as you breathe in and move down as you breathe out.
- 'Breathe low and slow, relax, let go'
If you are finding that you're taking short, fast breaths from the top of your chest, taking slower, deeper breathes from your tummy may help to ease breathlessness

Breathe a rectangle

You should be breathing out roughly twice as long as you are breathing in. To help visualise this, some people like to picture a rectangle (as shown below). Wherever you are, there is often a rectangle to be seen, this might be a book, tablet screen, computer, TV, door, window, table top or even a picture on the wall.



What positions can I use to help my breathing?

Leaning forwards with your arms supported on a wall or table



Sitting forward with your elbows on your knees or on an armrest



Altered Taste and Smell

After Covid-19, some patients complain of altered sense of smell. This can be experienced as a diminished (you have some smell but it's not normal) sense of smell or complete loss of the sense of smell. Some patients experience usual smells as bad odours. Some patients smell odours such as burning or smoke when there is actually no odour there at all. When this happens after a respiratory infection, it is called "Postviral olfactory dysfunction." It usually returns to normal on its own over weeks or months. From our own experience so far, as well as studies published by other covid clinics, we know that smell returns in most patients by 12 months. For some patients, this may be longer. We don't know why it is, but in some cases may be due to reinfections with covid or influenza.

Did you know? Most of your taste is come from your sense of smell so as your sense of smell returns, your sense of taste will change, too.

If it is reducing your appetite, experiment with different flavours, textures and temperatures to see which you find more palatable. Try using herbs, spices, pepper, chutneys and pickles in cooking. For recipe ideas this free cookbook is available to download online: <https://lifekitchen.co.uk/product/taste-flavour-digital-book/>

If you find foods have a strong smell try foods that are cold or foods served at room temperature. Choose foods that do not have to be cooked i.e. sandwiches, crackers and cheese, cold cereal, milk, milkshakes, or smoothies. If you go off a particular food, try it again regularly as your tastes may continue to change. If foods have a metallic taste, try plastic cutlery instead of metal.

Safety Note: Your sense of smell is really important for your safety. While your sense of smell is affected, be certain that your home smoke detector and carbon monoxide detector are working. Always double check that you have natural gas appliances to be sure that you have switched them off. Be vigilant about food safety and storage recommendations, and the "use by" dates on food.

Make sure smoke detectors and carbon monoxide alarms in the home are working. You may not smell a gas leak, so be vigilant about turning off gas appliances. Carefully read "Use-by" dates on food labels. Write opening dates on food and discard strictly within time frame. For expert advice on storing food and use-by dates, check: <https://www.safefood.net/food-storage>

Smell Training: For some patients, current evidence suggests that smell training may help recovery. **Absent.org.uk** has excellent resources for patients, including how to do smell training at home and make their own kits.

Fatigue

Fatigue has been reported as one of the most common symptom experienced by those with COVID-19. It is one of the most troubling symptoms and one that affects people most.

Fatigue is a feeling of weariness, tiredness, or lack of energy. It can be physical, cognitive, or emotional, mild to severe, there just some days or every day. It can affect your energy, motivation, and concentration. Fatigue can affect your sense of well-being and quality of life. It interrupts or stops you doing your usual activities. People experience varying degrees of fatigue and fatigue can be physical or mental/cognitive in nature. It is important to recognise your own experience of fatigue and what is manageable for you.

However, it is difficult to objectively measure (it means doctors can't test you for your level of fatigue, for example.) In this clinic, we ask you to complete questionnaires that ask you to the impact of your fatigue. This helps us monitor the impact it has on you and how you are recovering.

Current international expert recommendations for fatigue management and recovery:

- 1 Paced, structured, and individualised return to activity.***
- 2 Energy conservation strategies.***
- 3 Healthy diet pattern and hydration.***
- 4 Treat any underlying medical conditions that may be making fatigue worse***

One of the important things we do in the clinic is make sure there isn't treatable reason making your fatigue worse. For example, some patients have new high blood sugar or new low thyroid after a virus, and this can be part of the fatigue. Many patients also report very poor sleep, which needs to be treated to help improve fatigue symptoms

For many people, coping with and managing fatigue may be a very new experience. Therefore it will take time to adjust to the impact of physical fatigue and to learn to manage it as best you can. Accepting that you are experiencing fatigue will make you better able to manage it. We also know that recovery from fatigue looks different for everyone and will take time, patience and practice.

“Graded Exercise” and Long Covid

Patients tell us they have been given this advice and it doesn't work for them. We agree. We do not recommended “graded exercise” or “exercising your way out” of long covid. However, we also know that complete absence of any and all physical activity in chronic diseases, including long covid, can cause “deconditioning” and harm.

Note: Long Covid is NOT deconditioning. However, patients living with long covid can develop deconditioning symptoms in addition to their long covid symptoms and we should try to avoid that.

We have 101 reasons for recommending all patients to move - including protecting your heart, lung, bone, and muscle health, reducing pain and stiffness, helping with sleep, improving mood, and easing some gut symptoms, just to name a few. We just need to make sure our patients are not doing more than they are ready for.

What should you know?

Symptom-guided return to activity is recommended for patients with fatigue. Long-term, the goal of any rehabilitation program should be to restore patients to previous levels of activity. *But until that goal is reached*, patients should not engage in high intensity aerobic exercises or heavy weightlifting. If patients do too much, too soon it may worsen symptoms. Patients often usually experience rebound fatigue or “crash”, also termed postexertional malaise (PEM). This can lead to a pattern of “good days” followed by “bad days”, a pattern also called “boom-bust.” We know this cycle doesn't help recovery.

Discuss physical activity with your doctor first. When you are ready to start, we will be trying to have you work *under* your fatigue threshold. That is, only what you can do without triggering symptoms or provoking a crash.

How Do We Measure Fatigue

It would be great if we could just test patients to measure their fatigue, but we rely on what patients tell us about their symptoms. We believe patients. When it comes to whether it's mild or severe fatigue, it depends on the impact it is having on a patient's life. Here is a guide used in some international covid clinics:

Mild fatigue: Patients can walk, sit, and stand without difficulty and perform activities of daily living such as bathing and dressing. They can do tasks like light housework with difficulty. They are also able to continue working or going to school but usually no other activities that aren't necessary. They often require changes to their work/school duties or schedule, and may use weekends/days off to recover.

Moderate fatigue: Patients may have difficulty walking in the community, such as around shops. They have difficulty with activities of daily living like cooking or laundry. They require frequent rest periods, and are off work or school.

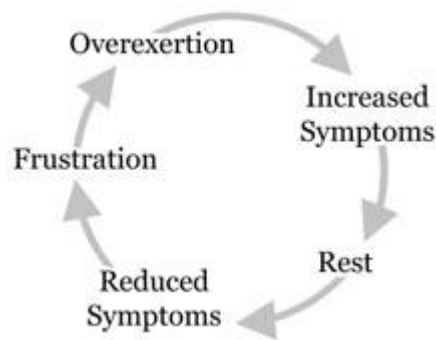
Severe fatigue: Patients mostly confined to the home and have difficulty with basic activities of daily living like eating, bathing, and toileting.

Management of Fatigue: Energy Conservation

Rest

Take breaks throughout the day. This is particularly important after activities that may make you tired such as walking down the corridor, getting out of bed or doing the shopping. Do not wait to feel tired before you stop and rest, aim to take a break *before* you start to feel fatigued. Taking frequent short breaks is better than infrequent long breaks as it enables you to maintain an even activity cycle throughout your day. Remember resting and taking breaks is individual to you. Try doing something you enjoy while you are breaking, such as listening to music or a podcast or doing some relaxation exercises.

Overexertion



Overexertion may lead to an increased feeling of fatigue so it is important to remember to rest and pace yourself.

The 4 P's:

1. Prioritise your activities and tasks for the day. Think about what 'needs' to get done and what you enjoy doing. It is important to reach a balance between the two. It might be helpful to think about what tasks require low, medium and high levels of energy.
2. Plan your day in advance. Using a diary can be useful when planning out your day. Make sure that the tasks and activities are well spread out and not all done in one go, or left till the end of the day. It is also important to plan and schedule times for breaks and rest.
3. Pace yourself. Break down tasks, take frequent breaks and gradually increase your activity day by day, if possible, based on your symptoms. We advise our patients that it is helpful to think of your energy levels like you would a phone battery, and pace yourself to get to the end of the day still having 5-10% left. Avoiding the "bust" can help avoid post-exertional malaise, or the "crash" after good days. Going to bed with the battery down to 0% can mean waking up the next day unrefreshed and the battery uncharged.
4. Positioning – Changing how you do some tasks can help manage your energy. For example, consider using a shower chair/bench for showering or sitting down at a kitchen table while preparing meals. Set up your work space so things are nearby so that you do not need to get up more than necessary to reach items or do tasks. Occupational therapy can be very helpful for patients in this aspect.

Remember – it is important to focus and notice what you can do rather than what you cannot do!



Return to Activity

The goal of rehabilitation is to enable you to return to your everyday activities. This may include your normal everyday activities like washing/dressing/housework or returning to work or exercise.

It is a good idea to log in a diary the amount of exercise you are doing each day as a means of monitoring your progress and setting goals.

Be mindful that returning to your previous level of ability is a gradual process.

Re-establishing Activities of Daily Living (ADLs)

- The body is made to be busy and upright so as soon as is possible it is helpful to be up, even in hospital setting.
- During the day, patients are encouraged to be out of bed towards rehabilitation gains. Walking to the toilet or sitting out for meals initially is important. Over time, progress to extended periods being up.
- Just like in hospital, if you are unwell at home, aim to be up as soon as possible, to prevent problems from too much bed rest.
- Carry out enjoyable self-chosen activities. For example, reading, music, films, baking, gardening, yoga. It is helpful to choose an activity enables relaxation and joy.
- To support energy conservation think about your positioning (e.g., how you stand or how you sit). Avoid excessive bending, reaching, stretching.
- Use comfortable work heights. For example, between waist and shoulder height is best.
- Consider doing some activities sitting. Use labour saving and adaptive equipment.
- Nature and daily fresh air are known positive health boosters.
- Noticing and appreciating your surroundings as you take daily walk is essential to good health
- Maintaining good relationships which offer you positive encouragement.

Headache

Some people with Covid-19 have regular headaches during their recovery. Here are some things that you can try to ease the symptoms at home:

Apply a cold compress to the painful area of your head. Try placing it on your forehead, temples, over your eyes, or to the back of your neck.

Take a warm bath or shower or try a warm compress to your neck and shoulders.

Rest if you are feeling tired.

Take a walk or break from something that you are concentrating on (such as screen or reading).

Ask someone to rub your neck.

Apply gentle, steady rotating pressure to the painful area of your head with your index finger and/or thumb. Maintain pressure for seven to 15 seconds, then release. Repeat as needed.

Rest, sit or lie quietly in a low-lit room. Close your eyes and try to release the tension in your back, neck and shoulders.

Try some of breathing exercises suggested in other sections of this booklet.

If you are getting headaches very frequently, start a headache journal. Record when you get each headache (date, time of day), how long it lasted, what helped/what made it worse, and any symptoms you had with the headache (such as nausea/feeling sick). Record if you took any medication. A journal can help you identify things that may be triggering your headache, such as poor sleep, skipping a meal, or stress.

Taking pain-killers for an occasional headache is safe. (This includes over the counter medicines such as Panadol) Taking them everyday for a headache can also cause a “medication overuse headache”. This is a headache that is there nearly every day. It gets better when you take medication but comes back when the tablets wear off. It can be very severe.

For patients who already have migraine before having Covid, their migraine may change after Covid becoming more intense or frequent.

For some patients, headaches may be a feature of autonomic dysfunction or dysfunctional breathing pattern, described in next section of this book.

Tinnitus

Tinnitus is a ringing or other noise in one or both of your ears that is not caused by an external sound and other people can't hear it. Tinnitus is a common problem; it affects about 15% to 20% of people. It is more common in older age. If you have new tinnitus after Covid-19, start with your GP to review your medications, check that ear wax isn't impacted in your ear canal, and review whether or not you should get audiometry (a test of your hearing). New hearing loss and impacted ear wax are two common treatable causes of tinnitus after a virus.

Try white noise (a machine, an app on your phone, or an appliance such as a fan) in your bedroom. The noise can help cancel out the tinnitus to help you sleep. Nicotine, caffeine and alcohol can make tinnitus worse in some people so you could try cutting back on alcohol and caffeine, or quitting smoking. Stress management techniques can also help.

You can get more information and find expert support at www.chime.ie/services/tinnitus-support-group.

Your Autonomic Nervous System Post-Covid: POTS and Dysfunctional Breathing

One area of research is the disruption of the autonomic nervous system in some patients following Covid-19 infection. This is not a new phenomenon post-covid. We have decades of studies on how autonomic disorders can develop after a variety of viral and bacterial infections, including influenza.

Current studies estimate that anywhere between 19% up to as many as 60% of long covid patient may have or may have had some amount of autonomic dysfunction.

What is your autonomic nervous system? The autonomic nervous system controls functions that your body does that you don't have to think about like your heart rate, blood pressure, digestion, temperature regulation, sweating, urination, and sexual function. There are a number of reason why autonomic deregulation can happen, and following a viral infection is one reason. Some patients get better quickly, some patients get better more slowly, some patients will have some autonomic dysregulation long term.

Symptoms are not the same for everyone. Symptoms may be mild or severe. Some of the common symptoms associated with this include POTS as well as feeling a pain or tightness in your chest, feeling tense or anxious, blurred vision, feeling dizzy, feeling confused, faster or deeper breathing (that you may not be aware of doing!), feeling short of breath or unable to get a deep enough breath, bloated feeling in stomach, tingling, cold, or stiff fingers, arms, or toes, tingling or tight feelings round mouth, or being aware of your heart beat (palpitations).

Many patients may also have:

1. "POTS" which is Postural [orthostatic] Tachycardia Syndrome. This means that the heart rate goes too fast when someone goes from sitting or lying down to standing.
2. *Dysfunctional breathing pattern is common.* A patient's breathing become deeper or faster or a combination of both. This can feel like becoming breathless. However, some patient only notice the other symptoms like chest pain, headaches, tingling or palpitations.
3. "OI" or Orthostatic Intolerance is when patients don't meet the diagnostic criteria for POTS, but have many of the signs and symptoms.

Why is self-management important? Many patients become less and less active due to their symptoms. They can start to become deconditioned, which can actually make symptoms worse for some patients.

For patients with autonomic dysfunction, good sleep, getting plenty of fluids (especially water), gently returning to physical movement and activity, and looking after mental health are key to feeling better. You can read more about it in the other sections of this book.

If you are worried that you have autonomic dysfunction, POTS, or dysfunctional breathing, make sure you talk to your doctor in clinic.

There is excellent evidence that shows that breathing exercises help patients with autonomic dysfunction. It can take regular daily practice for weeks before patients note an improvement. There are 3 options to try:

1. There are excellent resources on www.POTSUK.org. Even if you don't have POTS and only have dysfunctional breathing, the website has a section called "Breathe" with excellent resources including a video on relaxed breathing practice. Try to do this three times a day for a few weeks.
2. We would also encourage you to ask your doctor about whether you are ready to do the Pulmonary Wellness Bootcamp. <https://pulmonarywellness.org/42-day-bootcamp-week-1/>. This is a free, online, 42-day Bootcamp to help aid recovery in patients with symptoms of breathlessness.
3. Alternatively, we can also recommend this online programme developed by experts in Harvard: <https://research.bidmc.harvard.edu/info/flyer/longcovidbreathing.aspx>

Note: Always ask your doctor if participating in these programmes is the right next step for you. Some patients may need additional assessments or medication before starting recovery and rehabilitation.

Patient FAQ's

- **What do you offer for treatment?**

Many of our patients have come across clinics who offer trials of unproven treatments, especially clinics abroad offering everything from hyperbaric oxygen to plasmapheresis to anticoagulation treatments. Some patients expect us to do the same. However, there are patient protection laws, including patient safety and ethical guidelines, about trialing unproven medications on patients, and we adhere to best clinical practice. Some of these treatments have potential for harm or side effects. We will not recommend use of medications in cases where there is no evidence that they can help or there is a complete lack of sound scientific reasoning for their use.

We adhere to international best practice guidelines, which are always changing.

What we do know is this:

One of the most important things we can do is assess a patient's "functional history." We explore what you could do before Covid and your current ability to do your daily self-care activities and activities of daily living (e.g., bathing, dressing, cooking, cleaning, shopping) as well as whether you are able to fully participate in work, school, social, and family life. It's also important we ask about how this impacts mood. We know that living with these limitations causes stress, financial strain, and a feeling of isolation. We are very aware that many patients feel pressured to do these activities even when it makes their symptoms worse (such as post-exertional malaise.) Understanding is an important part of a patient-centered treatment plan that addresses physical needs, mood, and coping.

Understanding potential triggers for a patient's symptoms is part of this as well. These can be a variety of things, including menstrual cycles, medications, alcohol and drug use, stress, unemployment, social isolation. We are also aware that many of our patients have new or pre-existing co-morbidities (other diseases) such as new post-viral asthma or pre-existing arthritis that is now worsening.

Almost all of our patients will be screened for POTS and have blood tests during their first appointment. Most patients will have an ECG, which is a tracing of your heart beat. If you need a chest xray, we can do that on the same day. Some patients may need us to arrange other tests on a different day, such as pulmonary function tests (to test your breathing), sleep studies, or 24 hours monitors at home for heart rate or blood pressure.

Where necessary, we may refer patients to our colleagues in sub-specialty clinics in post-covid neurology or post-covid respiratory medicine. Where needed, our patients have access to clinical psychology and occupational therapy through this clinic.

- **How well do vaccines protect against developing long Covid if you have breakthrough infections?**

Early studies from UK, US, and Israel indicated there is some protection but that data is still out. Interpretation of those numbers will include accounting for variables such as time since vaccination and variants (this recently published study only looked at early 2021).

- **What causes post-Covid condition?** There are many theories. Some are supported by some promising early research. Mitochondrial dysfunction, serotonin, cortisol, immune dysfunction, viral reserve, autoimmune, autonomic system, microclots have all been suggested but there isn't enough evidence yet for any of them. Also: are we sure long covid is even one condition?

- **What is the most effective treatment for post-Covid condition?**

All of the best evidence to date is how to support recovery and rehabilitation. There is not evidence yet that any suggested treatment is a cure.

Looking for the cause of post-Covid Condition and what treatments might work is an international research priority. We collaborate with multiple centres of excellence abroad who are researching multiple treatments; the most promising studies that have not yet been completed (at the time this document was writing) are the NIH RECOVER group studies:

<https://trials.recovercovid.org/>

- **What is the 5 year, 10 year outcome?**

We can't know this yet because enough time hasn't passed. This is an important area of research both here and abroad.

- **When will I recover?**

We don't know. We know that our patients do recover, sometimes within weeks or after 2 years. In international studies, fatigue seems to improve by about 6% per month. The evidence suggests that rehabilitation and addressing any complications from Covid (like new asthma or new diabetes or new high blood pressure) does seem to help recovery.

- **What about the effects of the flu my recovery?**

Many of our patients reports significant set backs from infections with other viruses, including influenza or RSV, as well as re-infection with Covid-19.

- **Should I try Hyperbaric Oxygen Therapy?**

We cannot recommend Hyperbaric Oxygen Therapy to patients with post-covid symptoms. Many of the recommendations for hyperbaric oxygen therapy (HBOT) have come from those who have a financial interest in hyperbaric oxygen centres. The HOT-LoCo (Hyperbaric Oxygen Therapy in Long Covid) was a randomized, sham/placebo-controlled trial from the Karolinska Institute group. In this trial, HBOT did not improve long covid symptoms but was associated with increased side effects.¹ (This is an example of how international collaboration is helping patient care!)

- **Why aren't there more answers?**

Here are just a few of the challenges researchers around the world are facing as we work on this:

- **There are differences in how we're defining long COVID -**

This is important because there is a theoretical possibility that there isn't "one kind of long covid". It might actually be more than one condition, and this may be one reason the symptoms are so different among patients and some research doesn't make sense with other research. Some research includes patients who never had covid. Some research includes patients who have other conditions besides long covid. Some research includes only patients who definitely had a positive Covid test.

- **Lots of Data being mixed together can muddy the waters:**

How many reinfections a patient had and which variants also make this difficult to make sense of some data. In some studies, patients identified as long covid and/or reported their symptoms on an app - they were never assessed so we can't be sure that there isn't something else going on with their health after the virus. There are also huge differences among populations being studied: age, sex, gender, ethnicity, occupation, vaccination status – these things can all really impact health outcomes.

- **So many theories being looked at all at once:**

Possible viral reservoirs, insulin resistance, the role of serotonin, the role of possible microclots, immune dysregulation, possible lower skeletal muscle oxidative phosphorylation (mitochondria) capacity, autoantibodies, reactivation of other viruses, in particular EBV (Epstein-Barr Virus)

¹ Kjellberg A, Hassler A, Boström E, *et al*

Ten sessions of hyperbaric oxygen versus sham treatment in patients with long covid (HOT-LoCO): a randomised, placebo-controlled, double-blind, phase II trial

BMJ Open 2025;**15**:e094386. doi: 10.1136/bmjopen-2024-094386

Patient Questions on Research

Is there research in St. Vincent's University Hospital? Can I take part?

Yes, we have several ongoing research projects. It is completely voluntary, and you can discuss that with us at any time.

- **AIID (All Ireland Infectious Disease)** cohort began enrolling patients at a number of Irish Hospitals with infectious disease, including Covid-19 early in the Pandemic. This study continues to collect samples from patients alongside clinical data. This national study involves collaborators from all over Ireland who are working together. A few papers have been published from this data so far, including those looking at immune response and symptom clusters. Studies of this data have also been presented at national and international scientific meetings.
- The **National Irish Covid Biobank** has 2 objectives. To integrate future collection of COVID-19 samples/data and making them accessible for research and to maximise the integration of existing collections of COVID-19 samples/data. In short, there is a lot of data being collected, and bringing it all together will help us use it better to help patients.
- **ReCOVer** is our follow-up study starting in 2025, following up patients from our clinic for 5 years. This study hopes to answer important questions about long-term outcomes. Patients who are discharged from our clinic will be invited to take part.

Is there a treatment trial somewhere that you can recommend?

At the moment, no. However, we counsel patients who do their own research looking for a trial to talk to us before joining any trial. We are happy to help you look into joining. Advisory: Patients should never pay to be part of a research trial. *Legitimate and ethics-approved research trials will never ask patients to pay.*

What is going on that I can follow?

We are following the RECOVER trials in the US, and participate in regular online updates with them. Patients can read more and follow along at: <https://trials.recovercovid.org>
In short, if there is any early signs from these trials that something we aren't already doing that may help our patients, we will let you know!

Has research been done on use of LDN (low dose naltrexone) in Long Covid?

There is no good quality research on the use of LDN published yet. There is an ongoing randomised controlled trial at British Columbia Women's Hospital + Health Centre in Vancouver, BC, Canada that we are following. (At time of writing this document, the study is in recruitment phase.)

What is ELAROS and C19-YRS?

Starting in July 2025, our clinic will start using the C19-YRS app. Patients will be asked to use the secure app to self-report symptoms and health status. Within ELAROS' app, these scores are used to generate interactive charts overlaying these assessments to provide a an overview of the patient's rehabilitation journey. It can help with research and help inform clinical decision making. Read more: <https://c19-yrs.com/>

Appendix 1: Headache Journal

[illegible]

Appendix 2 – Fatigue Tracker

Using this scale of 1 to 5, record your energy levels in the diary:

- 1 No fatigue – able to do all normal activities.
- 2 Mild fatigue – able to do most normal activities.
- 3 Moderate fatigue – able to do some activities but need rest.
- 4 Severe fatigue – difficulty walking or doing activities such as cooking or shopping.
- 5 Extreme fatigue – needing to sleep or rest all day.

You may want to record days you have treatment or do a certain activity. This can help you see how what you do affects your energy levels. We have included some examples of what you might write in your diary. You can see these in the first line of the table.

Day	Morning	Evening	Night	Hours Sleep	Activities	Notes
1/1	2	3	4	7	Laundry, 10 min walk	3 rests, stairs made symptoms worse

Day	Morning	Evening	Night	Hours Sleep	Activities	Notes

Day	Morning	Evening	Night	Hours Sleep	Activities	Notes

Day	Morning	Evening	Night	Hours Sleep	Activities	Notes

Day	Morning	Evening	Night	Hours Sleep	Activities	Notes

Additional Practical Supports for your Recovery from COVID-19

St Vincent De Paul – 01-8848200

Citizens Information can also be helpful in relation to financial issues, legal issues, and employment rights. Tel: 076 107 4000. They have a call back service accessible via www.citizensinformation.ie

MABS – Money Advice and Budgeting Service MABS Helpline Tel: 0761 07 2000, Monday to Friday from 9am to 8pm helpline@mabs.ie

Aware – Supporting Light through Depression – 1800 80 48 48 They also have a number of online on-demand programmes on resilience, stress, sleep, and coping with Covid 19: <https://www.aware.ie/programme-type/adult-programmes/>

The Samaritans – FREE phone 116-123 – 24 hours a day, 365 days a year

Pieta House - provides free therapy to those engaging in self harm, with suicidal ideation, or bereaved by suicide. FREEPHONE 1800 247 247 – TEXT HELP to 51444

Jigsaw – offering support to young people – FREEPHONE 1800 544 729 They also have extra support such as a 1:1 live chat service and Live group chats – for people ages 12 – 25 years facilitated by a clinician – go to www.jigsaw.ie for more information

Mental Health Ireland – have a number of different tools and booklets to help maintain your mental wellbeing– they also have information for those supporting family or friends who are experiencing mental health concerns www.mentalhealthireland.ie

Abuse and Violence Supports

Women's Aid – Tel: 1800 341 900 – open 24 hours, 365 days a year

Men's Aid – Tel: 01-5543811 – 9am to 5pm - Monday to Friday

TUSLA – if you need to report/discuss a concern in relation to child
Tel: 01 9213400

HSE Safeguarding and Protection of Older Persons and Vulnerable Adults teams

- Wicklow, Dun Laoghaire and Dublin South East - Tel: 01 2164511

Email: Safeguarding.cho6@hse.ie

- Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West

Tel: 045 920410 Email: Safeguarding.CHO7@hse.ie

Bereavement

The Irish Hospice Foundation –

The Irish Hospice Foundation also has a bereavement support line open Mon to Fri 10am to 1pm – 1800 80 70 77

Supporting Young Children

ISPCC – the ISPCC has a wide range of supports on their website, including a support line open from 9am and 1pm Monday to Friday – Tel: 01 522 4300, email: ispcc@ispcc.ie

Parentline – Parentline is a national, confidential helpline that offers parents support, information and guidance on all aspects of being a parent and any parenting issues - open 10am – 9pm Monday to Thurs, Fridays 10am – 4pm. Tel: 1890 927 277

Online resources

Stress Control Programme Online is a 3 week programme is free of charge to the public and delivered by Dr. Jim White, Consultant Clinical Psychologist, Stress Control Ltd. The programme helps participants recognise the signs of stress. It covers topics including how stress affects our bodies and our thoughts. It teaches skills to overcome panicky feelings and tips to getting a good night's sleep. www.stresscontrol.ie

My Notes:

[illegible]

