





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

St. Vincent's University Hospital

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Infectious Diseases Department, St. Vincent's University Hospital, Elm Park, Dublin 4

Direct telephone line: (01) 2215525

Web address: www.stvincents.ie

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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 verv 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 a proportion of 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 or long COVID are the terms that are used when patients continue to feel unwell for weeks or months after their initial infection". We know that this is an aspect of the pandemic that is still often overlooked, but we know that it can cause significant suffering for both those affected and for their families. A recent definition of long COVID has been proposed:

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. The most common are listed below:

Gastrointestinal symptoms (digestive system)	Psychological/psychiatric symptoms
	 Symptoms of depression
• Abdominal pain	• Symptoms of anxiety
• Nausea	
• Diarrhoea	Ear, nose and throat symptoms
Appetite changes	• Tinnitus (ringing in the ears)
Musculoskeletal symptoms	• Earache
	• Sore throat
• Joint pain	• Dizziness

• Muscle pain

• Loss of taste and/or smell

Dermatological symptoms

• Skin rashes

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 Suite 5, Herbert wing, in St Vincent's University Hospital and runs every Thursday (excluding public holidays) from2pm.

The clinic offers medical review under the supervision of a specialist in Infectious Diseases, with links to other specialties, including cardiology, respiratory medicine, psychology, physiotherapy and neurology, 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. Data to date has shown that 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. For example, people that did not require admission to hospital or people who never needed extra oxygen to help them breathe.

If you are experiencing ongoing symptoms post COVID, it is important to see your healthcare provider to make sure that there is no underlying cause for these symptoms. Underlying causes may include asthma, inflammation of the heart, or high blood pressure. Your healthcare provider will 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.

HSE resources and the "Live Well" National Programmes to support people with Long Terms Health Conditions Including Long COVID.

In addition to the resources in this book it is recommended that patients attending the Long COVID clinic utilse HSE resources and attend the HSE Live Well Programme.

- 1. The HSE website has a guide to managing the symptoms of Long COVID. <u>https://www2.hse.ie/conditions/covid19/long-covid/living-with/</u>
- 2. The HSE run a free group course called **Living Well** for anyone living with a health condition. You can meet others living with a chronic health condition and learn ways to help yourself.
 - The Dublin southeast programme is held in various locations in the area. You can sign up by contacting Triona McNamee: Phone: 087 405 3880;

Email: LivingWellCHEast@hse.ie

- The Dublin North programme has a specific group for people living with Long COVID which is held online and is open to anyone in the country. Contact Leah Harrington: Phone: 087 365 4392; Email: <u>LivingWellDNCC@hse.ie</u>
- Information for other groups can be found on the HSE website, see: <u>https://www.hse.ie/eng/health/hl/selfmanagement/living-well-programme/</u>

Understanding self-management

Although the term "self-management" can be used to also mean many things such as selfcare, 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 dayto-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, and your diet.

How to Support your Physical Recovery

This section of the booklet will help to guide you in your physical recovery after COVID-19. The purpose of this section is to:

- ✓ Keep you active and mobile
- ✓ Give you exercises to improve your strength if you have become weak after your diagnosis
- ✓ Work with you on strategies to decrease breathlessness and manage fatigue

The advice provided is based on the most recent research, and may change as further information becomes available.

If you feel unwell exercising please contact your GP.

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, and recommendations may change.

However, early data from multiple physiotherapy-led programmes 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.

Why is physical activity important? Physical activity is an essential part of health for everyone, including those recovering or those with chronic illness. In addition, if patients are not active for long periods of time after illness or injury, they can become deconditioned. Deconditioning can worsen symptoms, and can slow recovery.

How much to you need? If you feel like getting started, start small! Try to do 10 minutes, and no more than a moderate intensity. To find your moderate intensity, use the "talk test": You should be able to speak a sentence while exercising. If you can whistle or sing you could try push yourself a little harder. If you can't speak a sentence you need to slow down.

Additional expert information on returning to movement after physiotherapy can be found at:

https://askthephysio.ie/post-covid-rehabilitation-guide/

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. It is important to rebuild your muscles and fitness levels as soon as possible after your illness.

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 are helpful to commence 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 any of these exercises cause you pain or discomfort then cease them.

Beginner Exercises







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

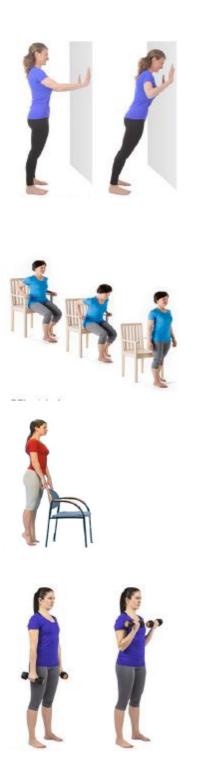
Sitting in a chair, alternately lift your legs up as if you are marching on the spot.



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



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.

Breathlessness

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

- *Pace yourself:* Only go at a speed that is comfortable for you, slow down to control your breathing
- <u>Take rests</u>: 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
- **<u>Relax or distract</u>**: 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

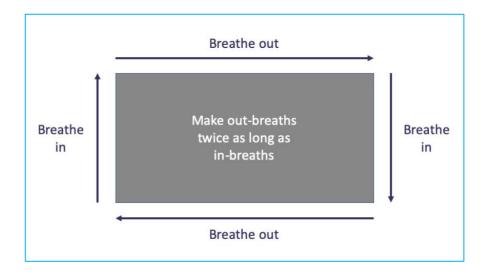


Relaxed Tummy Breathing

- 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 <u>not</u> 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.
- '<u>Breathe low and slow, relax, let go'</u> 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





Physical Fatigue

COVID-19 affects your breathing and can also impact your energy levels. 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 can be defined as a feeling of tiredness or exhaustion and can result in lower activity levels. It is a feeling of extreme exhaustion that 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.

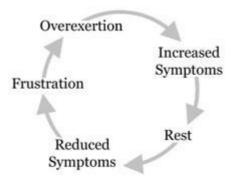
For many people, coping with and managing fatigue may be a very new experience. Therefore it will take time to adjust to the impact of physical fatigue and to learn to manage it as best you can. Accepting that you are experiencing fatigue will make you better able to manage it. We also know that recovery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

Management of Fatigue

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.

Pacing

As discussed above, pacing is a method of increasing your activity level without worsening your fatigue. You should aim to have an even level of activity throughout the day. Instead of doing a lot at once, spread it out evenly.

The 3 P's:

- 1. <u>Prioritise</u> 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. <u>Pace</u> yourself. Break down tasks, take frequent breaks and gradually increase your activity day by day.

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.
- If you are unwell at home, aim to be up as soon as possible, to prevent the adverse effects of extended 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.

How to support your Nutritional Recovery

It is important to eat well to support your recovery from COVID-19. COVID-19 can cause fever, cough, general weakness, 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:

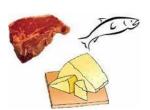
- ✓ Give you ideas on how to meet your body's nutritional needs
- ✓ Provide tips for eating well to manage any side-effects after COVID-19.

1. Tips for eating well

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 improve muscle strength and function. Aim to have a portion at each meal. Great sources include:

- Red meat (beef, lamb, ham and pork)
- o Chicken or turkey
- Fish (salmon, sardines, trout, tuna and kippers)
- o Eggs
- o Beans, peas, lentils, Quorn or tofu
- o 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 include bread, cereal, rice, pasta and potatoes.
- 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
 - \circ $\,$ Oily fish such as sardines, pilchards, mackerel, herring, salmon and trout
 - o Eggs

It is recommend that all adults in Ireland should take a daily supplement of 20-25ug/day (800-1000 IU/day), where possible and medically appropriate. For more information see: <u>https://www.oireachtas.ie/en/press-centre/press-</u> <u>releases/20210407-oireachtas-health-committee-launches-report-on-addressing-</u> <u>vitamin-d-deficiency-in-ireland/</u>

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 cap I do?
Problem	What can l 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.
	Try to have nourishing drinks (milk, milkshakes, smoothies) after your meals, 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
	Do not use low fat or diet products. Usual healthy eating advice is generally inappropriate in these instances. Focus on eating high energy and protein foods such as cheese, high fat and Greek yogurts, peanut butter, cream cheese, or cream soups made with whole milk.
	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.
Swallowing	If you are finding it difficult to swallow, are frequently coughing during meals or your voice becomes "gargly", ask your healthcare professional to refer you to a speech and language therapist to check your swallowing and for further advice.
	If you have problems with swallowing (dysphagia) and have been given advice from a speech and language therapist please continue to follow their advice concerning the texture of your food and drink.
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, or use ready-meals, tinned foods or a meal-delivery service if you are finding cooking tiring.

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.

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:

- Check the opening times of your local supermarket; they may have reserved certain times for older or vulnerable people.
- Use meals on wheels services or home delivery services offering pre-prepared meals.
- If you are self-isolating ask family, friends or your carer for help with your shopping. Check if a delivery service is available from your local supermarket.
- Arrange to eat regularly with a friend or family member using video calls.
- 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:

- Ham, corned beef, sardines, tuna, mackerel, salmon
- Baked beans, spaghetti hoops
- A variety of tinned fruits and vegetables
- Rice pudding, semolina
- Ready-made custard
- Soups and sauces

Dry Foods:

- Breakfast cereals, cereal bars, biscuits, crackers
- Pasta, rice
- Skimmed milk powder
- Packet soups and sauces
- Instant mash potato
- Nourishing drinks (Complan or Build up shakes/soups)

Frozen Foods:

- Breaded or plain fish / fish fingers/ breaded or plain chicken
- Roast potatoes/ oven chips/ potato croquettes/ potato waffles
- Frozen vegetables
- Ice-cream, frozen yoghurt
- 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

Symptom Management

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. For some patients, this may be many months and we still aren't sure why that is.

Did you know? Most of your taste is really 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.

- 1. Make sure smoke detectors and carbon monoxide alarms in the home are working.
- 2. You may not smell a gas leak, so be vigilant about turning off gas appliances.
- 3. 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, smell training may help recovery. Olfactory or smell training typically involves deeply sniffing at least four different odours for 10 seconds twice daily for at least 12 weeks. The smells used should be distinct and strong and include **flowery** (such as rose), **fruity** (such as lemon), **aromatic** (such as clove), and **"resinous**" (these are smells like pine, juniper, eucalyptus). Other odorants such as cinnamon, vanilla, orange, and banana can also be used. If you want to try it, this is easily done in your own home, and does not require any purchase of a commercial "smell training kits". Common household items that can be used include freshly cut citrus fruits at room temperature, spices or extracts for cooking, and vials of essential oils. In the few trials done, smell training didn't work for everyone and experts are still unsure how helpful it is for patients.

Headache

Some people with Covid-19 have regular headaches during their recovery. Here are some thing 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 every day for a headache can also cause a "medication overuse headache". This is a headache that is there nearly every day, even when you get up. It gets better when you take medication but comes back when the tablets wear off. It can be very severe.

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). Hearing loss and ear wax are two common treatable causes.

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 <u>www.chime.ie/services/tinnitus-support-group</u>

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.

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, and 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.

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.

Breathing exercises can help patients with autonomic dysfunction. It can take regular daily practice for weeks before patients note an improvement. There are 2 options to try:

- 1. There are excellent resources on <u>www.POTSUK.org</u> including a video on relaxed breathing practice. Try to do this three times a day for a few weeks.
- Buteyko Breathing techniques. You can learn more about it at <u>https://www.buteykobreathing.org</u> If you work with a teacher or therapist, we recommend choosing one who is also a registered Allied Health Professional. Note: one aspect of Butekyo suggests taping your mouth; we do *not* recommend taping your mouth.

Reducing Harm during Your 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 may 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**. If you need help quitting smoking or vaping, ask your GP or your doctor at your next clinic appointment.
- 3. **Consume media and social media cautiously**. 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, radio, 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 is 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 in clinic. Follow current public health recommendations, including washing your hands and wearing masks in healthcare settings and on public transport.

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. As well as learning to manage physical symptoms, it can be helpful to learn new skills for managing your mental wellbeing. Our minds and bodies are very much interconnected. Our physical symptoms impact on our mood, and also our recovery from physical illness is influenced by how we feel. Therefore it is important to look after both your body and mind during this difficult time.

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 and/or seek support with your mental wellbeing. 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.

Sleep

People may have changes to their sleep quality and quantity following their COVID experience. In particular, if you were hospitalised you may have very noticeable changes to your sleep pattern as your sleep wake cycle may have been quite disrupted in hospital. Following a COVID infection people have described 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. For some people, they may be sleeping far more than usual as their body has an increased sleep requirement.

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. 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 winding down. Beaumont hospital have an excellent library of resources to get you started: <u>http://www.beaumont.ie/index.jsp?p=528&n=532&a=0</u> (see also <u>www.cntw.nhs.uk/resource-library/relaxation-techniques</u>).
- Meditation may also be helpful, but can take practice. See Beaumont hospital resources <u>http://www.beaumont.ie/index.jsp?p=528&n=532&a=0</u>
- 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.



- You cannot force yourself to go to sleep, so do not try. See if you can use the time to rest instead.
- Don't do anything stimulating. Read a book or do something relaxing (e.g. listen to calm music, a sleep story or relaxation exercise).
- 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.

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 simple 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). See also Beaumont hospital resources: <u>http://www.beaumont.ie/index.jsp?p=528&n=532&a=0</u>
- 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 your find yourself caught up in the past or future much of the time. See Beaumont hospital resources: http://www.beaumont.ie/index.jsp?p=528&n=532&a=0 (Some people do not find mindfulness helpful. If that's the case for you try to focus on the tools that do help you).

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, 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 can create a number of traumatic experiences for many people. 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. 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:

Reliving the trauma in your mind and body		Avoiding things to do with or related to the trauma		
	Traumtic Event			
Feeling more irritable, tense or over-alert than usual		Feelir	ng depressed, Crying	

The following are some very common reactions after a traumatic event:

Tips for Supporting Adjustment

- Experiencing images and flashbacks of traumatic events is your brains way of trying to make sense of your experience.
- Having an understanding of the four main experiences people often have after a traumatic event is important.

- 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.
- 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.
- 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
- 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 a "grounding" technique to help you to stay in the present. The 54321 (or 5, 4, 3, 2, 1) method is a grounding exercise designed to manage acute stress and reduce anxiety. It involves identifying 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell, and 1 thing you can taste.
- 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, grounding).
- Try to remember that you are not to blame for your illness or symptoms
- Practice becoming more kind and understanding towards yourself when you are experiencing difficult emotion.
- If your trauma symptoms are very distressing or ongoing it is important to consider psychological therapy which you can access through your GP or you can refer yourself directly (see services and contact details directly).

A guide to Psychological Supports and Resources

HSE and voluntary sector Programmes for mental Wellbeing

The HSE have an online video series called **Minding your Wellbeing** where you will find advice and exercises to encourage your wellbeing <u>https://www2.hse.ie/healthy-you/minding-your-wellbeing-programme.html</u>

The HSE offer a 6 week course to help manage stress and anxiety.



This can be found at: www.**stresscontrol.**ie

If you would like support with getting more involved with your community, becoming more active or finding other sources of support (e.g. financial assistance), **social prescribing** can help you. <u>https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/mental-health-and-wellbeing/social-prescribing/</u>

Aware has a number of online on-demand programmes on resilience, stress, sleep, and coping with Covid 19: <u>https://www.aware.ie/programme-type/adult-programmes/</u>

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

Counselling and Therapy

It can be helpful to **talk to a therapist or counsellor** about the difficulties you are experiencing.

Free and low cost options:



For anyone experiencing low mood/depression, **Aware**'s support telephone service is available 10am-10pm on 1800 80 48 48 and

support groups are also run. See: www.aware.ie



Counselling in Primary Care is a short-term counselling service available to all medical card holders, on referral by their GP or self-referral by ringing 091 583 682. See: <u>www.hse.ie</u>



www.turn2me.ie offer up to 6 free counselling sessions to adults

Silvercloud is an online platform offering self-guided CBT. You can ask your GP to refer you. More information can be found here: <u>https://www.silvercloudhealth.com/ie/hsedigital-mental-health</u>

My Mind provides discounted counselling and psychotherapy for people who are unemployed, working part-time, in receipt of disability or illness benefit, studying or retired. You can refer yourself at :www.mymind.org

If you are healthcare worker, you may be entitled to the **Employee Assistance Programme (E.A.P).** It supports employees with psychosocial issues, whether they are personal or work-related. It is Free and completely confidential (neither your employer or your Occupational Health will be notified that you have used the service). You can read more about it and refer yourself at: https://healthservice.hse.ie/staff/benefits-andservices/employee-assistance-programme-staff-counselling/ or ring: 0818 327 327

Private psychologists, counsellors and psychotherapists:

Private Insurance: Many private insurance plans cover or reimburse at least 6 sessions of therapy. If you have private insurance, it is worth checking your policy.

Fully accredited and experienced therapy options:

- 1. Qualified and experienced Psychologists can be sourced through the Psychological Society of Ireland's online directory: www.psychologicalsociety.ie
- 2. Qualified and experienced Psychotherapists can be sourced through the Irish Association for Counselling and Psychotherapy: <u>www.iacp.ie, and also www.iahip.org</u>
- 3. The table below lists some psychologists and therapists in private practice. You can also ask your Long COVID team for local recommendations.

Organisation/Name/	Website/Contact Details			
Mind and Body Works	<u>Counselling & Psychotherapy in Dublin Find a</u> <u>Therapist (mindandbodyworks.com)</u>			
	Available nationally			
Clinical Psychology	www.clinicalpsychologyireland.com			
Ireland Connected Minds, Psychotherapy, Psychology, Ireland	DrKarenKeoghPsychologist@gmail.com- 0872538740			
	Based in Bray (Wicklow)			
	www.connectedmindspsychology.com			
	Contact: janine@connectedmindspsychology.com- 0831301383 - 0831301383 –			
	Based in Sandyford, Dublin			
Dr. Tim Dunne - Attachment and Early Trauma Specialist	emdr-dublin.ie			
	Contact:tpdunne@protonmail.com- 01-661-3788			
	Based in Dublin 2			
The Irish Centre for Compassion Focused Therapy	www.irishcentreforcompassionfocusedtherapy.ie			

Dr. Katie Baird

The Consulting Clinic	www.theconsultingclinic.ie
The Psychology Collective	www.psychologycollective.ie
Dr. Damien Lowry	http://damienlowry.com
MyMind	www.mymind.org

If you are concerned about your mental health, please tell the Long COVID team, or talk to your G.P.

If you NEED HELP NOW for yourself or for another person:

CALL 999: in the event of an emergency;

- A & E: visit your Accident & Emergency Department;
- GP: talk to your GP;
- CALL A HELPLINE: Ring SAMARITANS 24/7 on freephone number <u>116-123</u> or call Pieta House_Helpline (24hr): <u>1800 247 247</u>
- Simply text HELP to <u>51444 (Pieta House)</u>
- Email: jo@samaritans.org (email response within 24 hours)
- Web: <u>samaritans.org</u> **SAMARITANS** Longstanding & trusted, Samaritans volunteers provide confidential support, befriending and listening to those in personal crisis, 24 hours a day, 365 days a year.

How to Support your 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, but it is likely that these difficulties will be more of a challenge for those that had severe illness.

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.

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 (see p 35).

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.

Cognition, Brain Fog and Cognitive Fatigue

Some people who were hospitalised with severe COVID had neurological events which caused cognitive changes. Additionally, people who had mild illness and were managed in the community have reported problems with their thinking and concentration.

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.



Brain Fog

Many people with long COVID are troubled by a variety of cognitive or thinking difficulties which is sometimes referred to under the umbrella term "brain fog". 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 unable to think quickly or take in large amounts of information.

Cognitive Fatigue

Many people have experience of physical fatigue to some extent in their lives following illnesses or significant exercise. 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. Mental or cognitive fatigue a worrying experience with long COVID.

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

Some people find it hard to focus their attention for periods of time and can be much more easily distracted by background noise. This makes things like engaging with tasks for long periods of time difficult. It might be much more challenging to do two or more things at once.

Executive Functions

Executive functions are 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 can find it difficult to get started on tasks, organise themselves and to see tasks through.

What causes brain fog, mental fatigue or cognitive difficulties in long COVID and what can I do?

For some people there may be clear neurological events (e.g. stroke) that impact their cognition after having COVID. However, for most people, living with Long COVID, there is no clear biological injury that we know of that causes these symptoms. It is likely that a combination of biological factors (e.g. possible brain changes associated with the COVID infection, some medications, hormones, fatigue) and psycho-social factors (anxiety, depression) contribute to these symptoms.

Some lifestyle factors can be modified to improve cognitive function (e.g. sleep, diet and exercise). We know that brain fog can be impacted by many of the psychological difficulties discussed previously in this booklet. For example, our level of fatigue, anxiety and low mood may impact on our ability to concentrate and attend to information. If you cannot concentrate on something, it will be much harder to remember it.

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

- Make sure you use any aids you require, such as glasses or hearing aids.
- 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 using aids to support memory and planning, e.g. diaries, calendars, to do lists, alarms and reminders on your phone. It is important to use **one management system** rather than using multiple diaries/calendars. Get in the habit of checking this at a particular time, e.g. first thing in the morning.

- 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 task.
 Break down the activity into individual steps to avoid feeling overwhelmed.
- Keeping a **regular routine in your day** of sleep/wake times, movement, rest, nutrition and hydration. Routine is really important as once a routine is established as a habit, it takes less cognitive effort to plan tasks as you have less to remember.
- Ask people to **repeat information** or simplify what they are saying if you are feeling overwhelmed
- If you fail to remember something or make an error, try to be kind to yourself and do something to relax. It's normal to feel frustrated when this happens, but when you are feeling like this; you are less likely to be able to think clearly. Take a few minutes to calm down e.g. try deep breathing as discussed previously.
- Take care of your **physical health** e.g. nutrition, movement and sleep (see previous sections) as these are known to impact on cognition.
- Managing stress, anxiety, difficulties with low mood and sleep can also help to improve your cognitive function. In particular, managing anxiety and learning to focus your attention through mindfulness practices can benefit your cognition. See the previous chapter for more information.
- It may be helpful to discuss the challenges you experience with your family and friends so they can support you and so you can come up with helpful coping strategies together.
- We do not recommend any brain training programmes. For some people these can add stress which in turn will impact on your mood, anxiety and sleep, and potentially increase brain fog.
- If you would like to stimulate your brain chose an activity you like, e.g. puzzles, word and number games or reading. It is important to choose tasks that are achievable and enjoyable as this will help with motivation and feeling a sense of mastery or achievement. If you would like to

challenge yourself, gradually increase difficulty over time. If you are not enjoying doing these activities, it might be best to stop and try something else. Additional Practical Supports for your Recovery from

COVID-19

Financial Issues

<u>St Vincent De Paul</u> - 01-8848200

<u>**Citizens Information**</u> 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 <u>www.citizensinformation.ie</u>

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

Abuse and Violence Supports

<u>Women's Aid</u> – 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: <u>Safeguarding.cho6@hse.ie</u>

- Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West Tel: 045 920410 Email: <u>Safeguarding.CHO7@hse.ie</u>

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

<u>**Parentline**</u> – 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

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 <u>www.jigsaw.ie</u> for more information

Appendix 1: Headache Journal

	Start/End	Intensity	Symptoms	Triggers	Medication	Relief
Date	Times	(scale 1 to	Before			
		10)	headache			

My Notes:	
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