

Living Well with Long COVID

This document includes the information from the Te Whatu Ora Waitematā website on Long COVID for easy printing. This information has been developed by Te Whatu Ora Waitematā to provide information for adults experiencing Long COVID and those supporting them. For information specific to children experiencing Long COVID please talk to a general practitioner (GP).

What is Long COVID?

Most people with COVID-19 recover and return to normal health after around 2–6 weeks but for others it may take up to 12 weeks before they feel like they are back to full health. There are some people who continue to experience symptoms longer than 12 weeks – for these people symptoms may change or new symptoms may develop.

Long COVID is the name given to the symptoms people have after at least 12 weeks since having COVID-19. You might also hear it called by other names such as post-COVID syndrome, long-haul COVID, or post-acute COVID syndrome (PACS). Long COVID is a new condition and therefore we are still learning about it and doing our best to update information as it comes available. Overseas it is estimated that up to one in five people who get COVID will go on to experience Long COVID.

There is still no internationally accepted definition but the World Health Organisation has developed the following 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.”

Do I have Long COVID?

Remember, it is normal to experience symptoms following a COVID-19 infection for a number of weeks as your body recovers. Although after 7 days you are no longer very contagious, which is why you can leave isolation, your body will unlikely be recovered. Your body will need some care and time to recover from the viral infection, even once you are out of self-isolation. However, if you are experiencing ongoing, changing, or new symptoms at 12 weeks or longer after the initial COVID-19 infection that are not explained by another condition, you may have Long COVID. The type and severity of ongoing symptoms vary among people. There is no standard medical test to diagnose Long COVID but your healthcare provider (e.g. GP) will be able to assess if you have Long COVID.

If you think you may have long COVID, please consult your healthcare provider. They will help you rule out other conditions and will suggest the next steps to manage your symptoms.

Some Long COVID common symptoms are listed below:

Fatigue

Fatigue is the overwhelming feeling of tiredness that does not get better with sleep. Fatigue can be physical or mental and can change at different times. Your normal daily activities may leave you feeling exhausted, you may have difficulty concentrating, and you may feel very low in motivation. Read more about fatigue and how to manage it in the Tips and Tricks section below.

Difficulty concentrating ('brain fog')

Brain fog refers to a range of difficulties related to your thinking skills. You may be thinking slowly, having trouble remembering things, or having difficulty concentrating or focusing on tasks. These symptoms may be interfering with your normal daily activities such as your ability to work and study and for some people will mean you are unable to work or study at all. Read more about brain fog and how to manage it in the Tips and Tricks section below.

Numbness in the hands and feet

Numbness in the hands or feet refers to altered sensations such as pins or needles or weakness in your hands and feet. You may even notice a combination of persistent pain, stiffness, numbness, or weakness in the arms and legs. It is a good idea to talk to a health professional if you are experiencing new or worsening symptoms.

Low mood

Experiencing COVID-19 or any persistent symptoms can be difficult and understandably may impact your mood. Low mood includes feeling sad, empty, irritable, disinterested, or having thoughts of harming yourself. Feelings of worry, fear, and stress are also not unusual when dealing with difficult symptoms. Decreased appetite, lack of energy, and difficulty falling asleep may also indicate low mood. Read more about managing low mood in the Tips and Tricks section below.

New or worsening urinary symptoms ('overactive bladder symptoms')

Urinary symptoms include increased urgency or frequency of urination, difficulty controlling urination, or involuntary loss of urine. You may wake up more often at night to urinate, experience pain, or struggle passing urine. It is a good idea to talk to a health professional if you are experiencing new or worsening urinary symptoms.

Muscle pain and weakness

Muscle aches, pains, and lack of strength are common after periods of reduced activity due to hospitalisation or self-isolation. Exertion due to exercise or challenging activity can also aggravate muscle pain or weakness. The pain or weakness may be specific to an area or can be more widespread.

Cough

Cough is a common symptom of COVID-19 that usually recovers within a few weeks. Cough can also be caused by gastric reflux or be triggered by a strong scent. Some individuals experience persistent coughing during eating or drinking.

Joint pain

Joint stiffness and pain are common after periods of reduced activity due to hospitalisation or self-isolation. Exertion due to exercise or challenging activity can also worsen joint pain. The pain may be widespread or specific to an area.

Fast-beating or pounding heart

An increased heart rate may be experienced due to many reasons with Long COVID. You may notice your heart is beating unusually fast with daily activity, when you change positions from lying down to upright or standing, or when you feel stressed. Chest palpitations or breathlessness may also be experienced alongside a racing heart. It is a good idea to talk to a health professional if you are experiencing chest palpitations or breathlessness.

Shortness of breath

Shortness of breath refers to difficulties with breathing including feeling an intense tightening of the chest or suffocation. You may become unusually breathless with exercise; even climbing the stairs may have you struggling to breathe. Breathlessness may also be caused by stress, anxiety, or coughing. Read more about breathlessness and how to manage it in the Tips and Tricks section below.

Chest pain

Chest pain can be a worrying symptom for people with Long COVID. Chest pain is often experienced due to many reasons unrelated to your heart such as muscle pain following exercise or indigestion. However, chest pain can sometimes indicate serious problems with the heart or lungs. Talk to a health professional if you are experiencing chest pain.

Persistent loss of smell or taste

Persistent loss of smell or taste can follow a COVID-19 infection. You may not be able to smell good or bad odours or be able to detect flavours in food, causing food to taste bland or have a metallic taste. This may impact the appeal of food and your dietary intake.

Dizziness

Dizziness after a COVID-19 infection can include feelings of light-headedness (feeling like you might faint) or feeling like you are spinning/moving. Dizziness can leave you feeling off balance and can be linked to ringing in the ears, hearing loss, eye strain and headaches. Dizziness can also be a symptom of Postural orthostatic tachycardia syndrome (PoTS) which is an unusual increase in heart rate that happens after sitting up or standing. It is important to talk to a health professional if you experience dizziness at the same time as other symptoms such as chest pain, a fast-beating heart or shortness of breath. Doing too much can make dizziness worse, so pacing can help. Read more about Pacing in the Tips and Tricks section below.

Headaches

Headaches refer to pain in any part of the head and are often accompanied by various symptoms such as sensitivity to light, nausea, or loss of appetite. Headaches are common following viral infection but do not mean that the virus is still in your body. Headaches can be triggered by certain foods, habits, or stress.

Stomach issues

Gastrointestinal changes can occur after COVID-19. These can result in stomach pain/aches, nausea (feeling like you will be sick), vomiting, diarrhoea, and reduced appetite. Eating a balanced diet and staying hydrated are important when recovering from COVID-19, and therefore you should seek the guidance of a health professional if these symptoms are resulting in weight loss or dehydration.

Patient Stories

The ongoing symptoms, lifestyle changes, and lack of information can be frustrating for people experiencing long COVID. Remember you are not alone; people all over the world are experiencing long COVID.

We asked some people who have experienced Long COVID what they would say to someone who was just diagnosed with Long COVID and these are some of the things they said:

“You're going to get better, but it will take time and everyone is different, so go easy on yourself.”

“There will be good days and bad days, so be kind and patient with yourself.”

“Be prepared that this is unlike anything else you've experienced and the journey out is long - be patient and try to stay positive, focus on the little things and celebrate every tiny step forward”

“There is no definitive timeframe for recovery. Take that pressure off yourself. Try find something that brings you joy in life. No matter how big or small. Its very hard to keep your mind off this illness but try to distract yourself. Find someone you can talk to who will just listen.”

Tips and tricks for managing Long COVID and looking after yourself

Managing Long COVID will be different for everyone as people's experiences are unique to them. Living with Long COVID can be really hard and challenging at times and therefore it is important to go easy on yourself during this time.

Sometimes you may feel alone but it is important to remember you are not alone, not only are there millions of people worldwide who have experienced Long COVID but there are health professionals that can support you during this time.

“Although it might sometimes feel like it know that you are not alone”

Long COVID doesn't just affect people physically it can also affect other parts of a person's wellbeing such as their mental health. To manage long COVID you need to take care of the different aspects of your life that support good wellbeing. The Māori model of health te whare tapa whā developed by Sir Mason Durie in 1984 uses the wharenuī (meeting house) and its four walls to symbolise the different dimensions of health that contribute to wellbeing. The connection with the whenua (land) forms the foundation for 4 dimensions. The wharenuī is strengthened by its four walls and secure foundation. Similarly, we are at our strongest when each dimension of our health is cared for. When any of the dimensions are challenged, we can draw strength from our foundation or another dimension to balance and strengthen our overall wellbeing. You may want to consider these different dimensions in relation to taking care of yourself during Long COVID:

- **taha tinana (physical wellbeing):** Experiencing long COVID may mean that you are dealing with challenging physical symptoms. The symptoms may not only change how your body feels but also how you move, grow, and take care of your body. Some key things to take care of your taha tinana during this time are to prioritise sleep, eat regular and nutritious meals, and be kind to yourself by gradually increasing your activity levels. Read tips on sleep, self-care, pacing, and exercise. All of which will help you strengthen your taha tinana.
- **taha hinengaro (mental and emotional wellbeing):** Experiencing long COVID can be difficult and impact your mental and emotional wellbeing. Taha hinengaro is not only about how you feel but also about how you communicate and think. Taking care of your taha hinengaro will help you better cope with long COVID and the challenges that may come with it. Some key things to nurture your taha hinengaro during this time are to reach out to your friends, whānau, and hoamahi (colleagues). Sleeping and eating well, staying active, and allowing time for relaxation are also important for your taha hinengaro. Read tips on self-care, sleep, coping with brain fog or cognitive changes, and how to talk about long COVID.
- **taha wairua (spiritual wellbeing):** There is no single way to view wairua. For some it involves faith and religious beliefs, for others wairua may be viewed as a deep sense of interconnectedness to the universe or the sacred. You may have beliefs, values, traditions, and practises that support your identity and help you connect with yourself, whanau, community, nature, or the sacred. Read some tips for self-care and strengthening your wairua
- **taha whānau (family wellbeing):** Taha whānau involves your well-being, those you care about, and those who make you feel like you belong. Taha whānau can include your extended relationships, including your friends, hoamahi (colleagues), and community. Strengthen your taha whānau by spending time with your loved ones or letting them help you with the challenges of Long Covid. Your whānau can support your identity and overall well-being. We know it can be challenging to explain to whānau what living with Long COVID feels like; you can find some tips to help with this later in this document.

Other cultures and groups also have similar models that include the different elements of health and wellbeing such as the Pacific Fonofale model of health developed by Fuimaono Karl Pulotu-Endemann. For more information about Pacific models of health visit <https://www.healthnavigator.org.nz/healthy-living/p/pacific-models-of-health/>.

The following are some tips and tricks that people experiencing Long COVID may find useful to help take care of themselves during this time and manage some of the symptoms they are experiencing.

Self-care/ Taking care of your taha wairua

When stressful situations such as Long COVID continue for an extended period of time, it is common to feel less able to cope with everyday tasks. You might feel stressed or notice changes in mood, concentration, and energy. Self-care helps reduce stress and feelings of frustration, improves low mood and concentration, and boosts your energy and happiness. By taking care of yourself you will be better able to cope with your Long COVID. Self-care includes good nutrition, quality sleep, exercise, and relaxation to help you recharge your physical and emotional batteries and strengthen your wairua.

Here are some activities and tips to help take care of yourself during this time.

Acknowledging the emotional impact of Long COVID

- Physical health conditions can often affect your mental health too, and Long COVID is not an exception to this. It is well understood that living with Long COVID has an impact on our mental health. It's important to acknowledge the emotions that arise for you and to seek help for these if needed. Some common emotional experiences including:
 - Feelings of isolation and loneliness. You may feel alone in your Long COVID experience particularly if your friends and family have no experience with the condition.
 - Low mood. It is normal to feel down when you are physically unwell or when you aren't able to do the things you want to do. Some people describe feeling flat or not getting as much joy from good things.
 - Anxiety, worry and fear. Worry and anxiety about your symptoms as well as worry about the impacts of these on your life such as your ability to work are common. With little known about Long COVID you may also be worried or fearful about the future and when your Long COVID might end.
 - Anger and frustration. You may experience anger and frustration about Long COVID or the lack of treatment and support
 - Feelings of grief and loss. There can be lots of reasons you might feel grief and loss, from grieving all the things you can't do now with Long COVID or you could be grieving loved ones who passed away from COVID-19.
- Know that these emotions are normal and valid, and there are other emotions you might feel too. These emotions may come and go but should not feel so overwhelming that you are not able to cope.
- **If these emotions become overwhelming or you are struggling to cope it is very important to talk to someone or seek help from a professional.** There is information about services available at the end of this document.
- Things that you can do that might help:
 - Try and have a daily routine and plan nice activities regularly.
 - Talk to people you trust about how you are feeling.
 - Practice relaxation, mindfulness, meditation or prayer.
 - Try to eat well, sleep well and exercise safely.
 - Join a support group, either face-to-face or online.

"An unexpected thing is the grief. I am grieving my old (busy, active, happy) life. I don't know when I will be back to my old life and I don't know how to get there. It is like being stuck in a very depressing copy of your life that is mostly revolving around the sofa and the bed - not revolving around my priorities.... Family, my friends, my work, my passions and my activities. I have become so homebound and so ill and I miss my old life. There is a real sense of loss "of the way things were" and a heap of uncertainty about how/when will I be well again...and this feels to me at the moment, a bit like grief."

Talking to someone

- Sharing concerns and challenges with whānau, friends or a professional can help to relieve stress and build resilience. If you don't feel up to in person catch ups remember keeping in touch via messages or over the phone is great too.
 - If you would like to talk to others with Long COVID you could join a support group.
 - If you would like to talk to a professional, there are lots of services available to talk to. Check out the 'Where to get help' section below.
- If you are not sure how to talk to others about Long COVID, you can find some tips in the 'Talking about Long COVID' later in this document.
- Remember, sometimes talking to someone about things other than Long COVID can help distract from symptoms and help to improve your mood. If you feel this might help you can tell people that you don't feel like talking about Long COVID right now and would prefer to talk about something else.

Spending time with people you love and who make you feel good

- Dealing with COVID can be difficult and isolating at times. It is important to stay connected with your loved ones to help you feel happy and healthy. Socialising with friends and whānau can not only be fun, but also allows you to talk about anything that may be bothering you, and to ask for help on tasks that may feel too difficult to do on your own.

Keep a gratitude journal

- Practising gratitude can improve your physical, psychological, social, and spiritual wellbeing. By feeling grateful we can improve our mood, sleep better, take better care of our bodies and minds, and improve our relationships with others.
- You can practice gratitude by keeping a journal and simply writing down three things you feel grateful for each day. You can do this at whichever time suits you best. You can also keep a visual diary of things you are grateful for by taking pictures. For example, you may be grateful for lovely weather on a sunny day. You can read more about gratitude and its benefits here: <https://www.healthnavigator.org.nz/healthy-living/g/gratitude/>

Spending time in environments that make you feel good

- Spending time outdoors and connecting with our natural world is important for our physical, mental, and spiritual wellbeing. You can enjoy the natural beauty that Aotearoa has to offer by exercising, gardening, reading, creating art outside, or having a picnic with your loved ones.
- If you live in an area where there is not much nature around, try bringing the outdoor to you with plants, flowers, herbs or even photos or paintings of your favourite landscapes. Read more about how to thrive with nature here: <https://www.healthnavigator.org.nz/healthy-living/w/wellbeing-how-to-thrive-with-nature/>

Prioritise good sleep

Sleep is necessary for your brain and body to repair and replenish your energy. Read some tips on how to improve your sleep quality in the 'Getting a good night's sleep' section below.

Eating well

- How we feel physically has an important relationship to how we feel emotionally. Regular and nutritious meals are important to replenish your energy and ensure that your body is getting the vitamins, minerals, and proteins that it needs to support your daily life. Now may not be the time to make big changes to your diet, but often simple changes can make a big difference, for example: choosing a wide variety of healthy foods, increasing the amount of fruit and vegetables you are eating, and avoiding alcohol and smoking can all be helpful. Speak to your GP if you require particular help in this area or visit Quitline for support to quit smoking. Read some tips on eating well below
 - Eat plenty of fruit and vegetables. Fruits and vegetables are packed with nutrients to boost recovery and prevent a range of diseases. Eat a minimum of 3 servings of vegetables and 2 servings of fruit each day.
 - Try adding some breads, cereals, grains, and starchy vegetables in your meals to incorporate some whole grain and high fibre foods in your diet
 - Fish, chicken, legumes, and lean meat are great sources of protein and nutrients for a balanced diet.
 - Limit how much processed food, sugary food/drinks and alcohol you consume.

Try practicing relaxation

- Long COVID can be a stressful experience. Relaxation techniques can help you release tension and feel calm. These techniques have both physical and psychological benefits. Remember that relaxation is a skill, with some time and practise the full benefits of relaxation can be achieved. Try incorporating some of these relaxation techniques in your self-care routine.
- You can also try these breathing exercises which will help you catch your breath and ease feelings of worry and panic.

Calm and Relaxed

Close your eyes and take a few minutes to focus on your breathing. Breathing in through your nose if that feels comfortable for you.

- Gently place your hands on your stomach and notice how your hands rise and fall with the natural rhythm of your breathing.
- If you are finding it difficult breathing into your abdomen, press your hand gently down onto your stomach as you breathe out and then let your stomach gently push your hand back out as you breathe in. Sometimes it can be helpful to think of your stomach, as being like a balloon that is filling with air as you breathe in, and then gently deflating as you breathe out.
- As you breathe in through your nose, say to yourself ... 'calm', and as you breathe out, say ... 'and relaxed'
- Continue to breathe normally and naturally
- Notice the gentle rise and fall of your hand as you breathe in and out
- Continue to focus on your breathing for the next few minutes – repeating to yourself 'calm' ... 'and relaxed'

Muscle relaxing breathing

- Hunch your shoulders up to your ears as you breathe in, counting to 3
- Hold the tension for a count of 3
- Relax / let go of your shoulders as you breathe out, counting to 3
- Repeat this x 2

Coping with brain fog or cognitive changes

Brain fog, which you might hear referred to as 'cognitive dysfunction', is a commonly reported symptom of Long COVID. People describe their thinking being slowed down, having trouble remembering things, having difficulty concentrating or focusing on tasks, having trouble tolerating loud noises, and finding it hard to find the words to say things. These symptoms can have a big impact on usual daily activities such as work or study as well as the ability to socialise.

The cause of brain fog isn't well understood and appears to be somewhat individual. However there are some factors that we know can contribute to or worsen people's brain fog including pain, fatigue, shortness of breath, overdoing physical activities and changes in mood.

While there's no one-size-fits-all treatment that can cure these cognitive difficulties, there are things that we know can help you manage them:

1. Use pacing strategies to conserve your mental energy
2. Take regular breaks
3. Use a calendar or write things down to help your memory
4. Get good sleep
5. Engage in good self-care such as avoiding alcohol and drugs, and eating well
6. Engage in regular, safe amounts of exercise
7. Try regular relaxation, breathing exercises or meditation
8. Remind yourself that this is a common symptom of Long COVID and that you are not alone
9. Seek the help of a health professional if needed.

Here are some suggestions for managing brain fog from people with Long COVID:

"I put a white board in my room to note to dos. Then make a clear objective/goal I want to achieve each day before I start my day. Otherwise, I kind of just forget what I'm doing a lot."

"Take a break from screens. Listening to an audiobook or music can be relaxing. If you need to work on a screen, 15-30 min blocks then 10 minute rests work well."

"I have a whiteboard in kitchen that I note anything happening that week + grocery list, so I'm not worrying about forgetting things. Using calendar on phone for reminders."

"It's truly scary when your brain doesn't function like it normally does. It will improve but it takes time. Reading may be hard but treat it like exercise. Start with a few pages a day and build your way up if you have too. Meditate and practice relaxation techniques. They really do help more than any drug. There are free apps for this. They take time and practice to master. So be persistent and patient."

"Don't try and multi-task, now is the time to do one thing at a time. If you feel fog coming on, go lie down, close your eyes and take some really deep breathes. It's okay, you've got this."

"Work in smaller increments and go rest regularly to recharge. Partial workdays are much better to achieve this. The Brain Fog will gradually reduce over time. If you get a clear day/hours, try to manage excitement/expectations as it can be really easy to overdo it (with a big backlog of stuff) and the fog usually comes back."

"I keep a diary to record my symptoms. Record things to do I can't remember."

Managing fatigue and pacing

It is normal to feel tired or fatigued with Long COVID, however inactivity for long periods can worsen fatigue, muscle and joint pains, and other fitness and mood related symptoms. It is important to balance rest and activity, and to not forget about your enjoyment. Once you notice steady improvements in symptoms, you will be able to gradually increase your activity levels.

What people with Long COVID say to do to help manage fatigue:

“You can’t just push through this illness like you may have been able to in the past. Remove physical and mental stress as much as you possibly can. Start small. A walk to the end of the street and back. Over time slowly build up. It may be 100m further. Log the progress in a journal for your own sanity. Progress is very slow but it happens and you can lose sight of that.”

“Rest, rest, rest. But first, learn how to truly rest. Take time off work.”

“Rest. Don’t feel the need to do anything. Let it go. Now is the time to rest and let others do things for you.”

It is common for people experiencing Long COVID to have good days (where your symptoms aren’t as bad) and bad days (where your symptoms are worse). It is important to resist the urge to do too much on your good days which can lead to a cycle of ‘boom and bust’. Try to be patient and pace yourself.

Pacing is a helpful evidence-based technique used to increase daily activity and fitness while managing pain and fatigue symptoms. Pacing can allow you to steadily improve your activity levels without risking exhaustion or worsening any symptoms.

Long COVID symptoms may change how much activity you can manage, how enjoyable these activities are, or how long it takes you to do them. Pacing can help you manage symptoms such as fatigue, brain fog, muscular or joint pain and numbness. Pacing strategies can help avoid breathlessness, headaches, pounding heart, or worsening fatigue by preventing over-exertion.

Pacing can be split into three steps 1. Plan 2. Prioritise 3. Delegate

1. Plan: Planning each day in advance helps you to lay out any goals that you are working towards, or tasks and activities that you need to complete. Try building a daily routine and space out your activities and tasks to allow for rest and re-energising in between.
 - You may find it helpful to alternate between different types of activity e.g., alternating between mental and physical tasks.
 - Break up bigger tasks into smaller, manageable chunks. For example, instead of completing all your household chores in one day, complete one small chore each day.
 - Be sure to balance your essential activities with some enjoyable and energising ones.
 - Be flexible with your plans, if you feel too tired to continue, take a rest and try again tomorrow. Taking frequent yet short breaks are better than a few longer ones.
 - It is important not to be harsh on yourself by comparisons with other people’s experiences, or how much work you could do before long COVID. It may take a few tries to get your planning right.

- Once you notice a sustained improvement in symptoms, gradually increase your activity levels.
 - Keeping an activity diary can help you with planning and prioritising.
 - Tracking your symptoms can help you monitor improvement or identify persistent concerns that may need GP advice.
2. **Prioritise:** Experiencing symptoms such as fatigue or pain may make it difficult to manage your usual routines. You may find yourself being unable to meet your usual work or fitness demands. Remember to be kind to yourself, it is okay if you cannot finish all the tasks you wanted to complete in a day. Prioritising your activities and tasks can help you complete your important activities and essential tasks without over-exerting yourself.
- You may find yourself feeling more active during certain times of the day. Prioritise your important tasks by planning to do them when you have the most energy.
3. **Delegate:** Delegating or planning your tasks can help you save energy. Examples include doing your cooking in the weekend to prepare for the week ahead or grocery shopping online. Importantly, you do not have to go through long COVID alone. Reach out to your friends and whānau and let them help with challenging tasks such as shopping, preparing meals, or driving if they can.

“Your energy is precious. Dedicate it wisely. This illness can be both isolating and debilitating. Prioritise your mental well-being by staying connected and focusing on the things you love. This is more important than chores. Don’t be afraid to ask for help. You can always ‘pay it forward’ when you’re feeling well again.”

Managing headaches

Headaches are common during viral infections and usually disappear within a few weeks, however, some people continue to experience headaches many weeks or months after a COVID infection. The presence of a headache does not mean that the virus is still present. Many factors other than a viral infection such as diet, fatigue, lack of sleep and stress can contribute to your headaches. Long COVID headaches may be more frequently experienced in those who have a history of experiencing migraines or headaches. Try some of the tips listed below to help you manage headaches:

- Stress can be a common trigger for headaches. Practising self-care and relaxation techniques can be helpful to manage stress or changes in mood. Muscle relaxation techniques may be helpful to reduce stress, and tension in the neck and shoulders.
- A regular sleep schedule is important for your recovery and may help with pain, fatigue, and headache symptoms.
- If you identify triggers such as stress, alcohol, or caffeine, try to avoid them.
- Maintain a regular and nutritious diet and keep yourself hydrated during the day.
- If you experience feelings of exhaustion along with your headaches, try the pacing techniques in this document.
- Take your medications or painkillers as prescribed. It is a good idea to speak to your healthcare provider if you experience worsening headaches or dizziness.

Keeping track of your symptoms

Because long COVID symptoms vary so much from one person to the next it can be beneficial to track your symptoms. This will help you and your health professionals to better understand which symptoms you are experiencing and how these are impacting you, see if there are any patterns in your symptoms and monitor any changes over time. You can do this by noting down on paper, or on your phone, the type and severity of your symptoms and when you experienced them.

Getting a good night's sleep

Sleep (moe) is important on a physical, emotional and psychological level. Sleep allows our bodies to rest and recover physically, mentally and emotionally. Sleep energizes us and allows us to consolidate our experiences and information from the day. It also plays a key role in helping with our mood and emotional stability.

Sleep difficulties are common in times of stress or change. Experiencing long COVID can be stressful and this may lead to difficulties falling asleep, staying asleep, or waking up too early. Long COVID symptoms, racing thoughts, worry, or a disrupted routine may also be contributing to sleep difficulties. Sleep hygiene practises are effective in managing sleep difficulties and improving the quality of sleep.

Sleep basics

1. Avoid alcohol, nicotine, or caffeine intake for at least two hours before sleep
2. Remove any distractions from your environment including light and noise and avoid screen time for at least an hour before bedtime.
3. Do not go to bed hungry or thirsty but try to avoid heavy meals before bedtime.
4. Adjust your bedroom lighting, air quality, and temperature to your comfort if possible.
5. If you are feeling too hot or too cold, think about adjusting your bedding or taking a shower before bed.

Changing behaviour and other helpful practices

1. Stick to a regular wake and sleep time every day.
2. Create a bedtime ritual to prepare for sleep. Your wind down routine could include practising some relaxation techniques, listening to soothing music or a podcast, or enjoying a quiet read with warm milk or herbal tea.
3. If you feel worried or anxious when trying to sleep, try some relaxation techniques.
4. If you experience too many worries or spinning thoughts when trying to sleep, try scheduling a worry-time into your day. Scheduling a brief period for worry-time during the day will allow you to note down or discuss your worries with your whānau, so you can have a clear mind before sleep.
5. Keep a notepad at your bedside to jot down and park thoughts that pop up when you're trying to sleep
6. Do not complete work from bed, try to keep your bed for sleep and intimacy only. This will help you link your bedroom with sleep rather than your day activities so that your body and mind will know that when you go to bed it's time to sleep.
7. Prevent associating lying in bed with wakefulness. If you are unable to fall asleep within 30-minutes, get up from bed and do a quiet activity until you feel ready to sleep.
8. If you are really tired during the day, find time to have a nap. These shouldn't impact night time sleep if they are short (e.g., 30-minute power naps) and not too late in the day.






How to exercise safely

Exercise is important to improve strength, endurance, prevent health problems, reduce stress, and increase your energy levels. Symptoms such as fatigue, pain, breathlessness may make exercise difficult during this time. You may notice that your usual level of exercise, or even small amounts of activity have become difficult to manage. It is important to be aware that returning too quickly to intense exercise can worsen Long COVID symptoms. A gradual increase in exercise is important to safely manage your symptoms and prevent injury or exhaustion. If you are experiencing muscle or joint pains, feeling low in energy, or feel that your symptoms worsen after activity, try slowly increasing your exercise according to the five phases below.

Remember to stay on each phase for at least 7 days, and only move to the next phase if you do not feel fatigued or that your symptoms have increased. Drop back a phase if you experience setbacks in your symptoms.

Caution: *If you feel chest pain, dizziness, lightheaded, or nausea, stop exercising and contact your healthcare provider. See your GP for a referral to a physiotherapist if you have ongoing concerns about exercise.*

1. Phase 1 consists of gentle exercise that you can complete with ease. This phase focusses on preparing you for a return to exercise. Example exercises: Try practising breathing techniques, take a gentle walk, perform stretches, or balance exercises. You may do stretches while sitting or standing. Hold each stretch for 15-20 seconds.

	Reach your right arm up to the ceiling and then lean over to the left slightly; you should feel a stretch along the right side of your body. Repeat on the other side.
	Put your arm out in front of you. Keeping your arm straight, bring it across your body at shoulder height, using your other hand to squeeze your arm to your chest so you feel a stretch around your shoulder. Repeat on the opposite side.
	Sit on the edge of a chair with your leg out straight in front of you with your heel resting on the ground. Place your hands on your other thigh as support. Sitting as tall as you can, bend slightly forward at your hips until you can feel a slight stretch down the back of the leg that is stretched out. Repeat on the opposite side.
	Stand with your feet apart, lean forward onto a wall and step one leg behind you. Bend your front knee, keeping your back leg straight and your heel on the floor. You should feel a stretch in the back of your lower leg. Repeat on the opposite side.
	Stand up and hold onto something sturdy for support. Bend one leg up behind you, using the hand on the same side to hold your ankle or the back of your leg. Take your foot up towards your bottom until you feel a stretch along the front of your thigh. Repeat on the opposite side.

2. Phase 2 consists of low intensity exercises. You should not face any breathing difficulties while doing Phase 2 exercises. Example exercises include walking, doing light household or outdoor gardening tasks. If you can do these activities while holding a conversation with someone, you can increase the time you spend doing these activities by 10-15 minutes each day.
3. Phase 3 consists of moderate intensity exercise. Exercises in phase 3 may make you breathe heavily, but you should be able to have a conversation with someone while doing them. Example exercises are brisk walking, climbing up and down stairs, jogging, introducing slopes or inclines to your walks, and performing resistance exercise.
4. Phase 4 consists of moderate intensity exercises which also train your coordination and functioning skills. Example exercises are running, cycling, swimming, and dance classes.
5. Phase 5 involves you returning to your baseline exercises. At this phase you should be able to do the types of exercise and activities that you could do before you got COVID.

Talking about Long COVID

Talking to people about your experiences with Long COVID can be hard, particularly if they have no experience or knowledge of the condition. Although it's hard, trying to hide it from friends or whānau can be difficult and stressful.

Remember you don't have to tell everyone everything, take time to think about what you want to disclose and how much information you feel comfortable others knowing. Let them know what you need from them, such as practical or emotional support.

"Explain to others that you're unable to do what you used to be able to, it's hard to pull back from activities, but it's needed, or you just get worse."

Tips for talking about Long COVID with health professionals:

- It is useful to be prepared for appointments by writing down any questions you want answers to before you go into the consultation. If you have been keeping track of your symptoms make sure you take this information with you.

"If going to the doctor, prepare an iPhone note of your questions and symptoms so you don't have to try and remember them when you get there."

- It's ok to ask questions if you don't understand or want more information.
- If a doctor uses terms you do not understand it is ok to ask for clarification.
- It may be worthwhile taking notes during the session or take someone else along who can take notes for you so that you can refer to the information later on.

Tips for talking about Long COVID with your employer:

- It is useful to be prepared for conversations with your employer or manager, prepare notes in advance and consider having a support person present if you feel you want the extra support.
- Take time to consider what you need. For example do you need time off, more flexibility or changes in your duties.
- Talk to your doctor about documentation (e.g. medical certificate) if you think your employer might require this.

Coping with persistent loss of smell/taste

It is common to experience a loss or change in sense of smell and taste following a viral infection. Most individuals recover their sense of taste and smell within a couple of weeks of getting COVID, however, some individuals can take months to recover. If you are experiencing a persistent loss of smell or taste with Long COVID, try these tips below:

- Practise oral hygiene by brushing your teeth regularly and rinse your mouth with water if it feels dry or uncomfortable.
- A loss of smell and taste may make certain foods (kai) less appealing to you, however, it is important to have regular and nutritious meals to support your recovery.
- Unless you have been recommended a particular diet from your healthcare professional, you may find changing the flavour, texture, and temperature of food helpful. For example, you may prefer to add more herbs and spices to food if you are finding meals bland. Alternatively, if you have an unsettled stomach, you may find bland flavours easier to eat. Your preferences may change regularly, so it can be useful to retry certain foods and flavours over time.
- For a persistent loss of smell, try smell training by sniffing a lemon, rose, clove, and eucalyptus for 20 seconds each, twice a day.
- If you are having any difficulty in swallowing, or are struggling to maintain your weight, contact your healthcare professional to seek expert advice.
- If you continue to experience persistent loss of smell/taste, sometimes medications might help. Talk to a healthcare professional about your options.

How to manage breathlessness

Breathlessness may occur for a lot of reasons. If you feel out of breath during activities, or are struggling with cough, racing heart, or feelings of fear or panic then try these breathing exercises.

Calm and Relaxed

Close your eyes and take a few minutes to focus on your breathing. Breathing in through your nose if that feels comfortable for you.

- Gently place your hands on your stomach and notice how your hands rise and fall with the natural rhythm of your breathing.
- If you are finding it difficult breathing into your abdomen, press your hand gently down onto your stomach as you breathe out and then let your stomach gently push your hand back out as you breathe in. Sometimes it can be helpful to think of your stomach, as being like a balloon that is filling with air as you breathe in, and then gently deflating as you breathe out.
- As you breathe in through your nose, say to yourself ... 'calm', and as you breathe out, say ... 'and relaxed'
- Continue to breathe normally and naturally
- Notice the gentle rise and fall of your hand as you breathe in and out
- Continue to focus on your breathing for the next few minutes – repeating to yourself 'calm' ... 'and relaxed'

Muscle relaxing breathing

- Hunch your shoulders up to your ears as you breathe in, counting to 3
- Hold the tension for a count of 3
- Relax / let go of your shoulders as you breathe out, counting to 3
- Repeat this x 2

Your breathlessness should improve as you gradually increase your activities.

Changing position regularly can make it easier to breathe while in bed or can ease your symptoms during activities. If you get breathless during activities, try changing your position as pictured on the next page to ease your symptoms.

Positions to Ease Breathlessness:

	<p>Lying prone Lying flat on your stomach, or prone, can help breathlessness. It's not comfortable for everyone, but is a position to consider.</p>
	<p>High side lying Lying on your side propped up by pillows, supporting your head and neck, with your knees slightly bent.</p>
	<p>Forward lean sitting Sit at a table, lean forward from the waist with your head and neck resting on the pillow and your arms resting on the table. You can also try this without the pillows and rest your head on your hands.</p>
	<p>Forward lean sitting (no table in front) Sit on a chair, lean forward to rest your arms on your lap or the armrests of the chair.</p>
	<p>Forward lean standing While standing, lean forward onto a window sill or another solid surface.</p>
	<p>Standing with back support Lean with your back against a wall and your hands by your side. Have your feet about 30cm away from the wall and slightly apart.</p>

How to support someone with Long COVID

Supporting someone with Long COVID can be hard, especially when there is limited information about what their recovery will look like. Everyone's recovery from COVID and experience of Long COVID will be different and they will likely want different types and amounts of support, or even no support at all. To work out the most useful things you can do to support someone with Long COVID it is important to ask them questions about what they need and to listen with empathy and compassion.

1. Listen: The unknown aspect of Long COVID can be scary and stressful. Listening to their concerns and experiences can help make them feel less alone during this time. Take time to just acknowledge how they are feeling.
2. Ask questions: Knowing what to say can be hard. Ask them how they are doing as each day their symptoms might be different. Ask them what they need at the time and determine how you can help with what they need. For some people they may need practical support but for others they may just want someone to talk to. There will be times where you may not be able to support a person exactly as they need, and it's ok to acknowledge that. Just be direct in saying what you can and can't do.

These are things that people with Long COVID have described wanting others to know or understand about Long COVID and what they are experiencing.

"I wish people understood 'how are you?' can be a hard question to answer. Because long covid is a rollercoaster of unknown. That I may be looking ok and feeling almost normal right now, but suddenly overdo it (whatever that may mean at the time), and suddenly all Hell breaks loose and I'm back so many steps. I wish people realised we can't predict and plan. I wish people knew there isn't a one solution fits all. And that long covid is constantly changing my reality. And that I'm not coping as well as it may look. Everything is overwhelming, sounds, lights, information."

"Recovery is not linear nor does it happen suddenly. GP's can't cure long covid. Asking me if I am better yet, doesn't always help whilst it may be well intentioned. I may look ok but you can't see what's going on internally. Yes I may be anxious and depressed but it's not what is causing this. I am anxious and depressed cause being unwell day after day would take a toll on most people mentally after a while."

"Don't ask me if I'm better yet! Ask me how I'm doing today? This question I can answer."

"If someone has long covid... Offer to help them. Visit, but don't expect conversation (however for me I need some conversation as I really struggle with isolation). Do the dishes, weed the garden, take out the rubbish... Every little bit helps. And don't judge the state of the house. Our energy has to go to our physical needs, not used up on tidying and cleaning."

"People need to listen to the tears of someone who has Long Covid. Be patient and just sit with them. No words are necessary."

If you are supporting someone with Long COVID, remember that for you to be able to support them you need to take care of yourself first. Maintaining healthy behaviours (such as sleeping and eating well) and seeking additional support is an important part of helping other people.

If you are an employer or manager, you can play an important role in supporting your employees or colleagues with Long COVID. It is important to take the time to discuss with them what their needs are and work with them to establish realistic and supportive

expectations around their work. This may involve changes to their work schedule or working environment. Some tips include:

1. Provide a safe environment for employees with Long COVID to communicate about their experience and needs.
2. Take time to educate yourself about Long COVID. Having a good understanding on how long COVID can affect people and their ability to do their job is the first step to supporting them.
3. Consider how you can offer remote working or flexible working conditions and be open to change and adapt as peoples Long COVID changes.
4. Support awareness of Long COVID within your organisation to help increase conversation about it and reduce stigma.
5. Be supportive and empathetic!

Where to get help and more information

Phone Healthline free on 0800 611 116 any time of the day or night for advice on any health issue.

In an emergency, phone 111 for an ambulance.

Talk to your GP or health care professional

Please talk to your GP if you are experiencing Long COVID or ongoing symptoms from COVID-19. They will be able to refer you to the most appropriate support service for your needs.

Free Text 1737

For mental health support including anxiety and depression, free call or free text 1737 any time, 24 hours a day. You'll get to talk to (or text with) a trained counsellor or talk to a peer support worker. This service is free.

Ministry of Health

To read about what the Ministry of Health is doing to manage the long-term effects of COVID you can visit: <https://www.health.govt.nz/covid-19-novel-coronavirus/covid-19-health-advice-public/about-covid-19/long-covid#understand>.

To view the 'Clinical Rehabilitation Guidelines for People with Long COVID in Aotearoa New Zealand' go to: <https://www.health.govt.nz/publication/clinical-rehabilitation-guideline-people-long-covid-aotearoa-new-zealand>

ME Support – Navigating ME/CFS and Long COVID

ME Support have an online support tool that includes a series of videos with downloadable information for everyone who has, or thinks they might have, Long COVID.

<https://www.mesupport.org.nz/longcovidhelp>