Information for patients, families and support people

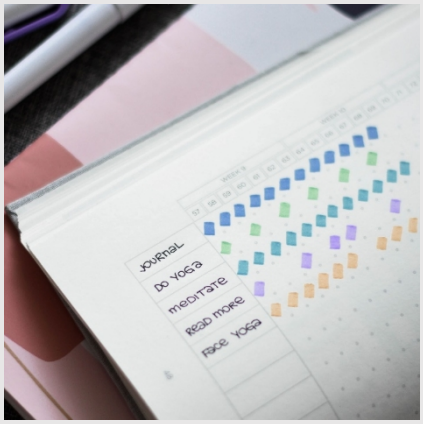
Post-COVID Service

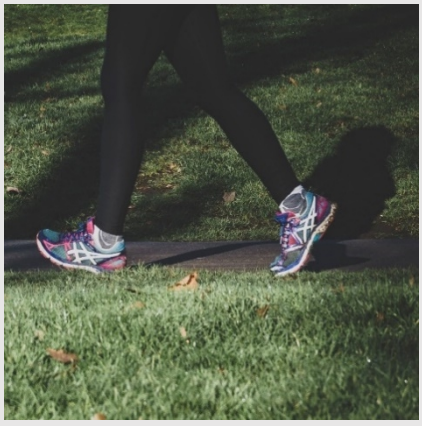
Changes in memory and thinking after COVID–19 infection













Neuropsychology Service
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What is Long COVID?

Coronavirus disease, also referred to as COVID-19, occurs when you are infected with the novel coronavirus (SARS-CoV-2). Some people with COVID-19 do not have any symptoms, while others experience a variety of symptoms ranging from mild to severe. We are still learning about the long-term impact of COVID-19 on the body. Recovery time is different for everyone, but for most people symptoms will resolve by 12 weeks. 'Post--COVID-19 syndrome' refers to symptoms that continue for 12 weeks or more, and involves a variety of new, returning, or ongoing symptoms.

People of all ages have been diagnosed with long COVID, including people with no underlying health conditions. The likelihood of developing post-COVID-19 syndrome does not appear to be linked to the severity of acute illness or need for admission to hospital. Any new or ongoing symptoms can fluctuate, affecting people in different ways at different times. Researchers all around the world are trying to understand why some people develop long COVID, while others recover completely.

Over 200 symptoms of long COVID have been described. The most common are:

- Fatigue
- Shortness of breath or difficulty breathing
- Difficulty thinking or concentrating (also referred to as 'brain fog')
- Headache

Other symptoms may include:

- Feeling tired or unwell after tasks or activities that require minimal effort
- Chest pain
- Fast-beating or pounding heart (heart palpitations)
- Sleep disturbance
- Mood changes, depression, or anxiety
- Joint or muscle pain
- Changes in ability to taste or smell
- Sore throat or cough
- Fever

- Nausea or diarrhoea
- Feeling dizzy or light-headed
- Changes in menstrual cycle, rashes
- Hair loss

'Brain Fog'

Most people who have had COVID-19 will recover with no long-term impact on their memory or thinking skills. Some people experience mild difficulties that don't last for long, while other people may experience problems that last for longer.

While there is no clear-cut definition of COVID-19 related 'brain fog', people are using the term to describe a group of symptoms that includes fatigue, slow or sluggish thinking, difficulty concentrating, forgetfulness, difficulty thinking of a specific word, and a general inability to 'think straight'. Up to 20% of people who have had COVID-19 have described symptoms of 'brain fog' weeks after they have recovered from typical COVID-19 symptoms, such as fever, cough, and shortness of breath.

Why does COVID-19 affect memory and thinking?

There are several reasons why people who have been unwell with COVID-19 might experience difficulties with their thinking and memory:

- Fatigue
- Fear/anxiety and low mood
- Direct effects of COVID-19

1. Fatigue

Fatigue is a feeling of severe tiredness. It is very common after viral infections, and it normally settles after 2 or 3 weeks. It can, however, linger for weeks or months in some people. Fatigue can affect your ability to concentrate.

You may feel that you don't have the mental energy to pay attention to things, even when they are important. If you can't concentrate on something, it is more difficult to remember it. If you have returned to work, concentrating on work tasks (particularly less interesting tasks) may be more difficult and exhausting.

What can I do to manage fatigue?

- Fatigue is real – be kind to yourself. Explain to your family, friends, and colleagues the impact that fatigue is having.
- Get a good night's sleep. Fatigue feels much worse if your sleep pattern is disturbed.
- Engage in regular relaxation or meditation exercises. These can help promote a good sleep pattern and reduce stress. There are many free apps that focus on relaxation and mindfulness, e.g. Smiling Mind.
- Engage in other relaxing activities that you feel you can achieve and that work for you. These may include sitting in nature, having a hot drink, gentle stretching, yoga, tai-chi, reading a book, having a long bath or shower.

- **The 4 P's: Plan, prioritise, pace and position**:
    - **Plan** each day in advance so that you can do what you need and consider what you can delegate to others.
    - **Prioritise** activities that are the most important to you and delegate less important activities (that still have to be done) to others if possible. Complete important tasks when you have the most energy. Say 'no' if others are placing too many demands on you. Think about areas where you can save your energy, e.g. online shopping rather than visiting the supermarket; cooking on the weekend for the week ahead.
    - **Pace.** It is important to manage your energy levels by pacing yourself. Aim to slowly complete tasks bit-by-bit over time. Take regular breaks. This will allow you to get tasks done, without spending all of your energy too quickly. If you try to complete tasks all in one go, you may end up feeling worse.
    - **Position.** Make physical adjustments to your body and environment to minimize energy use and fatigue. This might include sitting to do tasks instead of standing, maintaining a good upright posture, avoiding unnecessary bending and reaching, and creating a calm, distraction-free environment.
- Keep an activity diary. For 1-2 weeks, keep a record of what you have done during the day and how you feel after each activity. Also note if you have had a good day. Activities can be social, physical, cognitive (thinking), or emotional, and some can be more tiring than others.

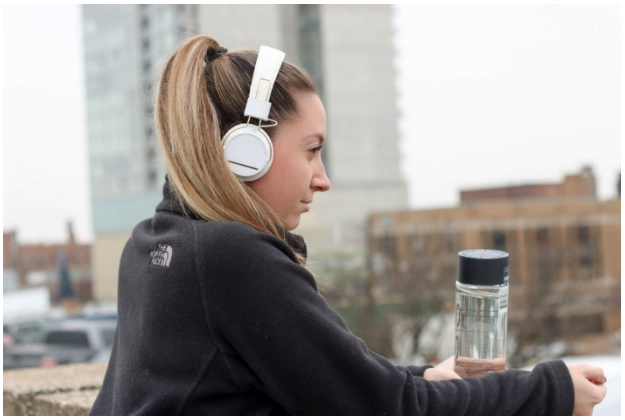
  Diaries can help you spot unhelpful activity patterns, such as irregular sleep or 'boom and bust' activity (where you are active on 'good' days and then feel exhausted the next day).
- You can include movement and physical activity into your day, as long as it does not increase your fatigue or cause an energy crash.



- Eat well. A healthy diet can help.
- The effects of fatigue can accumulate over time. Try to rest **before** you feel fatigued to prevent the fatigue from snowballing.
- Take regular 'moments' throughout the day to check on your fatigue level and need for a break. Effective rest breaks can be as little as 10 minutes.



- Try to engage in low stimulation activities, such as sitting quietly or listening to relaxing music, when taking a break.
- Learn to recognise your early signs of fatigue. These can include things like headache, feeling like your head or limbs are heavy, trouble regulating your body temperature, feeling irritable, or having trouble finding the right word when speaking.



- Fatigue can be triggered by busy or noisy environments. Try to minimise this by working from home, where possible, or working in a quiet space away from others.
- Jobs or activities that require multi-tasking or high levels of concentration (e.g. computer work, filling out forms, etc) can also trigger fatigue. It may be helpful to ensure that cognitively demanding days are followed by a 'rest' day where less challenging tasks can be completed.
- Switching tasks can sometimes help with fatigue, e.g. if you have been working on the computer for a while, switch to an activity where you can move around.
- Set realistic goals/targets for what you can accomplish in a day or over a particular time period, bearing in mind that you are likely to be slower to complete tasks when feeling fatigued.

2. Fear, anxiety and low mood

Feelings of fear, anxiety, and low mood can be common when living with long COVID. The stress of managing the condition, associated pain or fatigue, changes in lifestyle, loss of independence, and uncertainty about the future can significantly increase the risk of anxiety and depression, particularly in people who have a history of anxiety and/or depression.

Anxiety, worry, intrusive thoughts and images, and low mood can all affect concentration, and it is difficult to remember things, think through problems, and make decisions if you can't concentrate.

Fear and anxiety are understandable responses when faced with a frightening situation. For most people, the anxiety and associated physical and emotional experiences (e.g. difficulty breathing, raised heart rate, 'butterflies' in the tummy, intrusive images/thoughts) will gradually reduce over time. Other people may need additional support.

What can I do to manage my anxiety and fear?

- **Keep busy with other things.** When you are feeling particularly anxious, try distracting yourself by going for a walk or calling a friend.
- **Get back to normal activities.** Try to gradually start doing things that you've been avoiding because of your health worries, such as gardening or other activities that you enjoy. Remember to pace yourself when returning to these activities.
- **Try to relax.** Easier said than done when you are anxious, and different approaches work for different people:
    - **Slow breathing exercises.** When we are anxious or stressed our breathing can become shallow and rapid. Taking the time to slow our breathing down will encourage the body to relax. There are a number of different breathing exercises which have a similar effect.

      Here is one you can try

        - Place one hand on your breastbone and the other on your belly
        - Breathe-in slowly through your nose, feeling your belly rise (your chest should stay still) until you have a full breath - aim for 3-4 seconds
        - Slowly breathe out through your mouth with pursed lips, feeling your belly fall
        - Repeat 6 times
        - Practise daily

- **Visualisation.** Try to create a picture in your mind of a real or imagined place that brings about a sense of calm or relaxation. This might be an imaginary walk through a forest, imagining the smells and sounds, or it might be relaxing at the beach, imagining the sounds of the ocean, the rhythmic sound of the waves, and the feeling of the warm sun and ocean breeze on your body.

  Whatever works for you! You should find that you begin to breathe more slowly, and your muscles begin to relax.

- **Mindfulness meditation.** Try to focus your attention on the present moment, redirecting it back to the present when it starts to wander off onto worries and physical symptoms. It takes time and patience to learn, but there are many self-guided learning packages online or via an app (such as 'Smiling Mind'), or you might like to enrol in an instructor-led class.

- **Set aside a 'worry time'.** Trying not to worry about something can often make it worse. Consider setting aside a particular time of the day when you can think about your worries. If a worrying thought pops up outside this scheduled time, write it down to come back to later in your 'worry time'.
- **Engage in helpful/coping thoughts.** How we think about things affects how we feel. Try and engage in thoughts that help you to feel calm and help you to cope, e.g. *"I may need to take a bit longer to do things but that is OK."*

Avoid using alcohol or other substances to cope with anxiety

Low Mood

The following are all common signs of low mood:

1. Feeling sad or empty for much of the time (you may feel worse first thing in the morning).
2. Becoming more tearful than usual.
3. Feeling irritable and intolerant of others.
4. Losing interest in activities that you used to enjoy.
5. Finding it difficult to make decisions.
6. Paying less attention to your appearance.
7. Having thoughts of harming yourself or that you would be better off dead.

Some physical symptoms can also be related to low mood:

- Moving or speaking more slowly than usual.
- Decrease (or increase) in appetite.
- Lack of energy.
- Low sex drive.
- Disturbed sleep, for instance difficulty falling asleep or waking up early in the morning.

For most people low mood will improve on its own, particularly as you start to get back to doing things you enjoy and that give you a sense of accomplishment. Other people may need additional support. If some of the things aren't going to be possible for a while, or even at all, then finding alternatives will be important

What can I do to manage low mood?

It's easy to feel helpless when experiencing low mood, but it is possible to tackle this by focussing on the things that you are able to do and that bring you enjoyment, help you relax, give you a sense of achievement, and help you feel connected to others.

- **Stick to a routine.** People experiencing low mood can develop poor sleep patterns, such as staying up late and sleeping during the day. Try to avoid this by getting up at your normal time and sticking to your daily routines as much as possible.
- **Set achievable goals.** Make a daily plan of things you feel you can do that you enjoy and which give you a sense of accomplishment. Try to do something each day, within the limits of your energy levels.

- **Stay connected.** Don't withdraw from life. Talking to and listening to others can help improve our mood.
- **Eat well.** Try to make sure that you eat regular and healthy meals.
- **Avoid using alcohol or other substances.** People sometimes find that they start drinking more or using other substances to cope with or hide negative emotions, or to fill in time. Alcohol and/or substance use won't help solve your problems and can make your mood even worse.
- **Keep physically active.** Physical activity, within your energy limits, can help to lift your mood. You can include some movement and activity into your day if this does not make your symptoms worse, such as gently walking around your home or garden (if you have one).
- **Talk to loved ones.** Try to tell them how you are feeling. Talking about it can help them to understand and get rid of any misunderstandings that they might have (e.g. that they have done something wrong or that you have stopped caring for them). Try to take time during the day to share something positive that has happened, that you have seen or thought about, or that you are grateful for. Reflecting on even very simple things that we are grateful for has been found to be an effective technique for boosting mood.
- **Engage in helpful/coping thoughts.** How we think about things affects how we feel. Try to engage in thoughts that help you focus on the positives e.g. '*It might be slow but there are some improvements in how I am thinking/what I am able to do'*; '*I still enjoy spending time with my family/friends even if I can't do as much'*.

When should I seek help?

If after trying these strategies you are still experiencing high levels of anxiety and/or low mood that are interfering with your daily life and stopping you from doing things, get further help.

Talk to your GP, another health professional, or your existing mental health provider if you have one and tell them what you are experiencing.

Your **GP** can work with you to develop a **Mental Health Plan**, allowing you to claim up to 6-10 sessions with a mental health professional each calendar year.

3. Direct effects of COVID-19

Researchers are still investigating the long-term effects of COVID-19 on the body and the brain.

If you need to access urgent help

A number of free, 24-hour crisis services are available. These include:

- **Lifeline Australia**
  - www.lifeline.org.au
  - Ph. 13 11 14

Lifeline is a non-profit organisation that provides free, 24-hour telephone crisis support in Australia.

- **Beyond Blue**
  - www.beyondblue.org.au
  - Call a counsellor on the phone Ph.1300224635,
  - Chat to a counsellor online
  - Translation, speech and hearing services are also available

Beyond Blue is an Australian mental health and wellbeing support organisation. They provide support programs to address issues related to depression, suicide, anxiety disorders and other related mental illnesses.

Managing changes to memory and thinking

Problems with memory and thinking are common for many people who have had COVID. Discussing the problems you are having with those around you can help relieve pressure on everyone by allowing you to accept that there is a problem, think through together ways of coping, and allow others to help you.

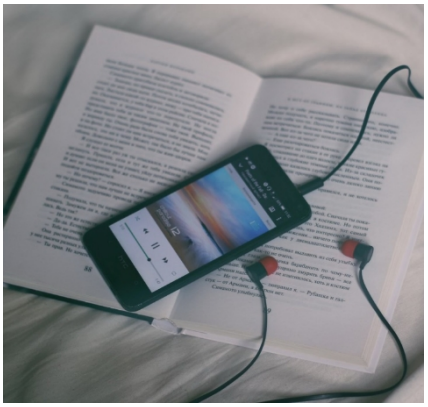
1. Attention and concentration

Problems with attention/concentration can make it hard to focus and ignore distractions. It may be more difficult to do two things at the same time and not be distracted when trying to concentrate on a task.

Ideas to help



- Try to focus on one task at a time. **Prioritise** what task to do first and try to finish one task before starting a new one.
- Try to limit distractions, particularly when doing something demanding like filling out a complicated form. Try to work in a quiet environment and/or ask others around you not to disturb you.
- Listening to gentle instrumental music can help some people. Check out music streaming platforms for 'focus' or 'concentration' playlists.
- Attempt more demanding tasks when you are feeling fresh.
- **Plan** regular breaks. It can be helpful to mix things up a bit by adding interesting tasks amongst more dull, routine tasks. This can help you get through the tasks you are less interested in.



2. Memory

If your ***memory*** is affected, you may find it difficult to hold information in your head in order to use it to make decisions. You may struggle to recall something that has happened or something you have been told, or you may forget to take medication on time.

'Out-source' your memory by using external aids to share the load. One of the most reliable and useful memory aids is probably within arm's reach – your mobile phone!

Ideas to help

- **Remembering to do things.**
    - Use your phone's calendar app or alarm to automatically remind you when you have to do things, e.g. put the bins out, take your medication, or attend an appointment or event.
    - If you don't have a mobile that has a calendar app or reminders, use a diary, paper calendar or whiteboard. Make sure that it has plenty of space for each day, and get into the habit of checking it regularly, e.g. at breakfast time and last thing before you go to bed.
    - Use lists for shopping/tasks to do, etc.

- **Remembering things that you have done**.
    - You can type notes into your phone, use the voice recorder to record a message, or take a photo.
    - Ask your health professional to write important information down for you, or if your appointment is via phone, you can ask their permission to record an important piece of information on your phone.
    - If you don't have a phone (or it is not with you), write the information down on a piece of paper. It can be helpful to get into the habit of carrying a notebook/diary ('memory book') and pen around with you.
    - Make sure you record information straight away.
- Keep important things (e.g. keys, wallet) in the same place at home to reduce the chance of you forgetting where they are.
- Repeat information so it is easier to remember (e.g. when taking a phone message, repeat the information back to the caller to clarify details) and ask others to repeat information if you feel that you missed something in conversation.
- Ensure you are paying attention when being told something you want to remember. Ask yourself, "am I concentrating?" and if the answer is no, re-focus and/or ask people to repeat what you missed.
- Only try to learn small amounts of information at one time, and if you need to take in a lot of material, ask if you can write notes and/or if the person can slow down and give information in short steps. It may help to ask what the key point is.

3. Executive function

Executive functions are the mental processes that allow us to solve problems, make decisions, plan ahead, and see tasks thorough to completion. They help us to deal with problems, such as organising a holiday, getting the car fixed, and finding a new job or a new place to live.

People with executive functioning problems often seem or feel disorganised and impulsive, and don't appear to or feel like they can think things through. They may find it difficult to get going on tasks, or they may start a task but not see it through, perhaps getting distracted by something irrelevant and not noticing that they have drifted off task.

Ideas to help

- **Routine** and **structure** will help reduce the demands on your brain.
    - Think through all the things you want to do regularly every day, or every week, put them into a schedule, and practice this routine until it becomes second nature.
    - Structure your environment. Having your environment orderly and free from distraction can help minimise the mental effort you need to exert to do a task.
        - Have the best lighting possible.
        - Have a place for everything to avoid having to search for it.

- **Planning**. Make a plan before approaching any new or complicated problem or situation.
    - It may help to break down large or more complex tasks/problems into smaller, manageable steps. Write the steps down in a plan and complete one step at a time. Keep checking your plan to make sure that you haven't gone off course, and to see whether you need to change your plan.
    - Make a list of 'things to do', then cross each off as you complete them. This can help you keep track of what you have done and what still needs to be done. That way you are not trying to hold all of the information 'in mind' while you work. You can also pick up where you left off if you need to take a break.

- **Stop** and **think.** Try to get into the habit of pausing during any complicated activity and taking a moment to think. Ask yourself: "What did I set out to do?", "How am I getting on?", "Do I need to change my approach?", or "Do I need to take a break?"

What if I'm continuing to have problems?

- If you are continuing to experience problems with your memory and thinking following your infection with COVID-19, and
    - These tips and strategies have not been effective in helping you manage your cognitive difficulties,
    - Your cognitive problems are resulting in:
        - increased absence/reduced performance in your education, work or training (e.g. unable to perform to your usual standard/reduced work hours);
        - difficulty managing home duties;
        - a significant impact on your relationship,

Contact the Alfred Post-COVID Service via email: postcovidfollowup@alfred.org.au for referral to our Neuropsychology Service.

Neuropsychologists are psychologists who specialise in understanding the brain and how changes to it may affect our emotions, our behaviour and our ability to think (cognition). They are trained to assess and treat people who experience difficulties with memory, concentration, planning, language, reasoning, and other aspects of learning and understanding.

Alfred Health generally has a waitlist for access to publicly funded Neuropsychology Services. While we try to triage based on increased need/urgency, there may still be a lengthy wait.

Other Services

- Talk to your GP, another health professional, or your existing mental health provider (if you have one) to see what support is available.
- If you are experiencing persisting mental health difficulties (e.g. low mood, anxiety), your **GP** can work with you to develop a **Mental Health Plan**, allowing you to claim up to 6-10 sessions with a mental health professional each calendar year (see Mental Health Care and Medicare).
- You can search for a psychologist (Generally Registered, Clinical Psychologist, or Clinical Neuropsychologist) via your preferred search engine, or via the Australian Psychological Society (APS) website (https://psychology.org.au/find-a-psychologist).
- **EMERGE Australia** is a national organisation providing education, advocacy, research and support services for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). People impacted by Long COVID can access Emerge Australia's existing support services including Patient Support and Information Services and the Telehealth Nurse Service. (https://www.emerge.org.au)

If you need to access urgent help

A number of free, 24-hour crisis services are available. These include:

- **Lifeline Australia**
  - www.lifeline.org.au
  - Ph. 131114

Lifeline is a non-profit organisation that provides free, 24-hour telephone crisis support in Australia.

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Contact information

Post-COVID service

55 Commercial Road, Melbourne, VIC 3004

Phone: (03) 9076 2000

Email: postcovidfollowup@alfred.org.au

Further information

American Thoracic Society Journals

Visit www.atsjournals.org and search 'Long COVID Patient Fact Sheet' or scan

If you would like to provide feedback about this information or request a copy in a different format, contact patientinform@alfred.org.au

Consumer REVIEWED

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