

# Enabling and Optimising Recovery from COVID-19



# Enabling and Optimising Recovery from COVID-19

*A handbook for health professionals  
and other caregivers of people with  
Long COVID*

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GEELONG



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# Version Information

## Version History

Here is a record of changes made to this textbook. Each edit is acknowledged with a 0.1 increase in the version number. The exported files for this textbook reflect the most recent version. Please refer to the version you have consulted in your citation or attribution of this work.

### **Version 1.0 – 08.08.2023**

- Original version

### **Version 1.1 – 15.03.2024** (*International Long COVID Awareness Day*)

- New content
  - Improving the participation gap: Physiotherapy for people experiencing Long COVID
  - Jesse Haslop persona
- Modified content
  - About this book
  - Foreword



# Dedication

*This book is dedicated to everyone with lived or living experience of Long COVID. We recognise and respect your ongoing resilience, persistence and courage.*

*We also acknowledge the care and support provided by health professionals and other caregivers to people with Long COVID.*

*May this book provide all readers with the knowledge, insights, and skills they need to enable people with Long COVID to live their best life.*

*We stand with you, we support you, and we are committed to working together to ensure better outcomes for people with Long COVID.*

# About the Editors



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=521#h5p-32>

# Foreword

***by Felicity Nelson***

I'm a science and medical journalist with Long COVID. I had always thought that if I became seriously ill in a country like Australia, there would be some kind of action plan. Doctors would prescribe medication or refer me to a specialist. There would be a guideline for best practice somewhere, and a few Cochrane reviews synthesising 20 years' worth of data. I would have options. Everyone would be sympathetic and nice.

It turns out none of those safety nets exist for people with Long COVID.

There was no action plan. Several GPs did not know whether I should continue working or rest. They could not advise on whether I should exercise or not. They could not explain any of my symptoms. There were no specialists to refer me to. The Long COVID clinics were not responding to referrals because they were already overloaded with patients. There were hardly any international studies trialling treatments for Long COVID. People were sympathetic initially and then didn't really know how to respond or forgot that I was still ill, or over-compensated in weird ways. And, at least in the early days, the Australian media appeared indifferent to the plight of people with this disease.

Until April 2023, there was no new government funding for research into Long COVID. I still do not know anyone with Long COVID in Australia who is enrolled in a study. I'm not, despite being keen. This inaction and complacency was inexcusable considering that Long COVID closely resembles myalgic encephalomyelitis/chronic fatigue syndrome – a condition that has been overlooked for decades despite causing a high burden of illness. So, having realised that my disease was part of a political battle that was yet to be won, I felt angry and ready

to act. But advocacy was emotionally exhausting, and I was not quite ready to admit to myself that this wasn't just a hangover from COVID that I would soon shake. Months and then a full year went by, and I was still not recovering.

And that's when I heard about this project: a handbook on Long COVID for health professionals and carers.

Reading this handbook, I am hit by wave after wave of relief that *finally* someone in healthcare *gets us*. The greatest strengths of this book are the personas, which are rich in detail and explain the complexity and diversity of Long COVID, and how it interacts with pre-existing conditions and circumstances. I really appreciate the effort that the authors have taken to represent diverse communities, including people of different ages, disabilities, sexual orientations, genders, ethnicities, and localities. I like how these personas detail everyday struggles that are often too mundane for doctors or friends to even bother asking about. I also appreciate the open, welcoming tone throughout, and how the book honours the patient experience and perspective. I feel very seen.

Long COVID is so hard to capture, study and explain because of its extreme unpredictability. People with the condition have good days, OK days, and shockers often without warning. Every person with the disease has a different set of over 200 symptoms, and these also change over time. Being fatigued, mentally foggy and in pain stuffs up other parts of your life in strange ways that then collude with your illness to make you sicker. It is bewildering. While there are no medications that cure Long COVID, that does not mean nothing helps.

Having a voice and being heard helps. Sensible handbooks like this one help.



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**by Wendy Hocking**

Filling out the new patient form in the dentist waiting room the other day, I ticked all the boxes about my health: no I don't have diabetes; nor respiratory issues; no history of stroke, cancer or heart disease; I don't take any medications; no known allergies; *any other serious medical conditions?* Does Long COVID meet the criteria of serious? I am a bit anxious – sitting in the dentist's waiting room will do that to a lot of people. I am also pretty tired. Despite planning for the day, having a good night's sleep, pacing my activity so I had enough energy to drive to the dentist – I am drained and finding it hard to think clearly.

I have had Long COVID a few years now and most days I understand how it affects me. However, there are still times when it feels like I am walking across shifting sands. Round and around in my head I go – am I tired because I overdid it a few days ago? Are my muscles aching because I have done too

much or too little exercise? Is the ringing in my ears a sound outside? Are the soles of my feet burning because I have been walking around without shoes on too much?

As this textbook acknowledges, we simply do not yet have the answers to all the questions Long COVID poses. The authors have expertly and in accessible language outlined what we do know. Yes, post exertional malaise is something people with the condition may experience, as is muscle pain, tinnitus, nerve pain, brain fog and my constant friend fatigue, along with a range of other symptoms. In this way the textbook helps those living with Long COVID place their experiences within frameworks to promote understanding. Most importantly, it takes a further step by providing information based on research to those working with, and caring for people with a range of seemingly unrelated symptoms that fluctuate in intensity and over time.

Not only does the textbook empower through enhancing knowledge of Long COVID, but also by incorporating the voices of those with lived experience. Having this as the core of a body of evidence is an incredible achievement for ordinarily scientifically based medical models of care. The online format is especially relevant so research and experiences can be added as our knowledge expands. For those of us with lived experience, it seems like a continual learning curve, as what was often taken for granted needs to be questioned and tested. This textbook feels like a guidebook that will continue to grow with us.

So back to the dentist's form... is Long COVID a serious thing? I have had to change a few things in my life since developing it. I moved to a cooler climate as I can't cope with extreme heat anymore. I changed my career path to a less demanding part-time role to aid in managing both my fatigue and brain fog. I replaced bush walks over rugged terrain with small sewing activities that are less physically demanding. Life is a lot smaller. My trip to the dentist will be all that I can manage

today before going home to rest. Social activities that used to be relaxing now need to be carefully planned so that I don't feel overwhelmed with chatter. This is all serious to me, and so I write Long COVID in the space for serious medical conditions.

I feel better once I have written it. If nothing else, the dentist might read it there on the form and it will provoke a thought either then, or the next time they come across Long COVID. It might prompt them to read an article about the condition next time they see it in the news. They may come across this textbook and decide to delve into understanding more about the condition, or contribute to the body of knowledge that is developing. If nothing else, I have put Long COVID on a piece of paper and it is out in the world. I feel like the butterfly flapping its wings, such a small movement but who knows what the reverberations will be. A small piece of energy returns to me.



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# Preface

*By Danielle Hitch*

I clearly remember entering the walk-in wardrobe that doubles as our home office and tapping my partner on the shoulder, *“This pneumonia thing in China seems really awful!”*. It was February 2020, and we were both becoming increasingly alarmed about a new virus called ‘COVID’. A week later, we pulled our kids out of school and started telling everyone we knew as much as we could about what was headed our way. Initially, no one really listened, or they thought we were overly dramatic, *“We’ll be fine; they’ll stop it way before it gets to Australia”*. Two weeks later, our entire community in Melbourne, Australia, entered the first of many lockdowns. And nothing would be the same again...



One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=529#oembed-1>

Communities all over the world experienced unprecedented disruption and dislocation. Video by [ABC News Australia](#).

The world continues to grapple with the ongoing COVID-19 pandemic, and over time it has become clear that acute infection is just the beginning for some people. As the initial wave ebbed, patients began to raise the alarm about distressing symptoms that persisted for months after their initial infection. These symptoms sometimes mimicked the



post-viral sequelae from other infections, causing fatigue, breathlessness and brain fog. However, many other problems were also reported by patients, who were often unable to receive care due to ongoing public health restrictions.

In October 2020, a partnership between Western Health and Deakin University called **WHCOVRE** was founded to investigate the mechanisms and experience of COVID-19 recovery to develop quality care that helped these patients achieve their best possible recovery. We soon discovered that COVID-19 rehabilitation was complicated, contentious and incredibly challenging. Little traditional evidence or expertise existed due to the novelty of COVID-19, and we were very aware of how little we knew. We turned to lived experience experts (i.e. our patients) to learn as much as possible about the syndrome and were grateful for their time, honesty and willingness to partner with us. This open education resource (OER) book results from this ongoing partnership and brings multiple 'ways of knowing' about Long COVID together.

The purpose of this book is to provide health professionals and other caregivers with quality learning resources to enable their practice with people recovering from COVID-19 infection. The learning promoted by this book is embedded within the lived experience of people with Long COVID, who have co-authored and/or peer-reviewed the content. The goal is for readers of this book to gain the knowledge and skills they need to support people with Long COVID in their recovery and management of an ongoing (and in many ways) uncertain illness.

Importantly, its publication as an OER means this book can be a living resource that can be updated regularly to reflect the rapid development of knowledge and practice in this area. New chapters will become available regularly, and existing chapters will be updated as new material comes to light. Anyone can contribute to this book, and I am looking forward to seeing it evolve over time to fit the needs of healthcare professionals,

other caregivers and (most importantly) people with Long COVID. This book is freely available to anyone with an internet connection – Long COVID is a global problem, and this is not the time to hide new knowledge behind a paywall!

Since the start of the pandemic, I have seen the impact of the COVID-19 pandemic on my local community. It has taken a huge toll on everyone, whether they've experienced a COVID-19 infection or not. But that toll is compounded and amplified for people living with Long COVID. As said by one lived experience expert;

“Long Covid has left me in this strange no-man's land of not knowing where I fit, neither ill nor recovered, one foot in each camp, one side more than the other depending on what day it is or what particular phase I'm going through.”<sup>1</sup>

I hope this book will help professionals, caregivers and patients to feel less 'lost'. Making quality information available to everyone as quickly as possible and explicitly focusing on its potential to improve daily life will give everyone firmer ground to stand on.

I freely admit I am no expert on Long COVID – I doubt any one person could be given its complexity and diversity. This isn't an old-fashioned book – you won't be able to read this once and walk away with everything you need. This is an ongoing conversation, and I encourage you to tell us what you want to read about. Please contact the editorial team at

1. Gahan, L. (2022). Breaking free from Long COVID: Reclaiming life and the things that matter. Jessica Kinglsey Publishers.

covidtextbook@deakin.edu.au anytime with comments, queries and recommendations.

We are all facing the same storm, even if we are not all in the same boat.



*Community spirit during the COVID-19 pandemic. Photo by [Anthony Quintano, CC BY 2.0](#), via Wikimedia Commons*

## References

# Acknowledgements

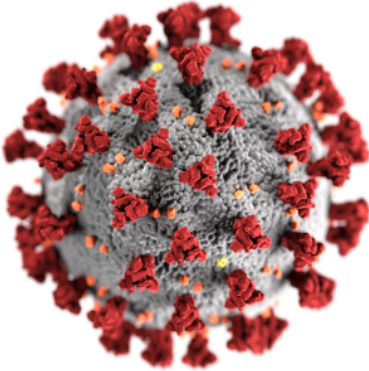
We acknowledge the Traditional Custodians of all the unceded lands, skies and waterways on which our editors, authors and readers come together. As we learn and teach through virtually and physically constructed places across time, we pay our deep respect to the Ancestors and Elders of Wadawurrung Country and Wurundjeri Country where our editorial team are located. We also acknowledge the many First Nations from where our readers join us and their vital contributions to our communities.

For opportunities to support and learn more about First Nations' health and well-being on Wadawurrung Country and Wurundjeri Country, please connect with:

[Weenthunga Health Network](#)

[Wathaurong Aboriginal Co-Operative](#)

# About This Book



*The COVID-19 Virus. "[SARS-Cov-2 without background](#)", by Alissa Eckert & Dan Higgins is licensed under [CC0 Public Domain](#)"*

*By Danielle Hitch*

Welcome to this online textbook about enabling and optimising recovery from COVID-19. The aim of this book is to provide health professionals and other caregivers with improved knowledge and skills for working with people recovering from COVID-19 infection or experiencing Long COVID. The information in this chapter is designed to help you get the most out of your reading experience.

The following information is adapted from the "[Open Education Resources Collective Workflow](#)" by the [Council of Australian University Librarians](#), used under [CC BY 4.0](#).

This online textbook is an Open Education

## Resource (OER)

An OER is an educational resource licensed to allow copying, re-distribution, and derivative works. It contains materials that contribute to an educational course, other studies and/or continuing professional development. There are many reasons to incorporate OERs into educational activities, including;

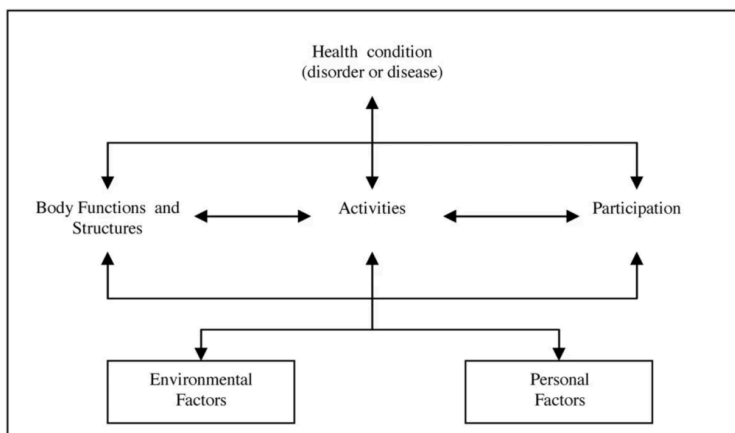
- **affordability** – every student or participant has access to the same learning materials
- **access and accessibility** – readers have permanent free access to resources in multiple formats
- **equity** – readers from low socio-economic, geographically dispersed or ethnically diverse backgrounds can gain equal access to quality educational materials
- **retention** – research indicates OER users [are more likely to complete](#) their studies than those using commercial texts
- **deeper learning** – OERs enable customised curriculum, which promotes [deeper engagement](#) for readers
- **diversity** – OERs can reflect diversity by including [gender-neutral language](#), culturally diverse examples and first nations representation and recognition.

OERs can take multiple formats, including courses, modules, course materials, textbooks (like this one), public domain books, audiobooks, videos, podcasts, interactive simulations, learning objects and primary sources. They are licenced for use under Creative Commons licences, which enable sharing and adaptation of existing resources worldwide.

## The content aligns with the International Classification of Function, Disability and Health (ICF).

The International Classification of Function, Disability, and Health (ICF) <sup>1</sup> is a way of categorizing health and disability developed by the World Health Organization (WHO) that considers physical, psychological, and social factors that affect a person's well-being. The ICF helps healthcare professionals, policymakers, researchers, and others communicate about health and disability using the same language and framework, making it easier to understand and address complex health issues <sup>2</sup>. The figure below illustrates the key concepts of the ICF, and their proposed relationship to each other.

1. World Health Organisation. (2001). International classification of functioning, disability, and health: ICF. World Health Organization.
2. World Health Organisation. (2002). [ICF Beginner's Guide: Towards a common language for functioning, disability and health](#). World Health Organization



*“Interactions between the components of ICF”, by [Nenad Kostanjsek](#) is licensed under [CC BY 2.0](#).*

As shown above, the ICF consists of two parts: Functioning and Disability (**body functions and structures, activities and participation**) and Contextual Factors (**environmental and personal factors**). The parts of this framework are reflected in the sections of this book but while content is arranged according to section, every chapter includes elements that touch on all of these domains.

Expect progressive publication with regular updates.

Another advantage of OERs is their ability to be rapidly and repeatedly updated. Given how quickly knowledge about COVID-19 has developed <sup>3</sup>, this enables responsive content that

3. Lipworth, W., Gentgall, M., Kerridge, I., & Stewart, C. (2020).



can be easily revised as new evidence comes to light. New and updated chapters will be added periodically and listed in the [Version Information](#) chapter. Be sure to cite the correct version in all attributions, as page and chapter numbers will change with additional or revised content.

If you want to join our email list to receive updates about new releases, please email **covidtextbook@deakin.edu.au** and provide your contact details.

This book has been co-authored by people with Long COVID (lived experience experts).

The editorial team are committed to founding the content of this textbook in the lived experience of patients. All personas and some chapters in the textbook were co-authored by the editorial team and a lived experience expert. Other chapters (written by researchers or clinicians) have been peer-reviewed by lived experience experts. Our intention is to ensure this textbook is a valuable, relevant and credible resource for anyone wanting to adopt a patient-centred approach to working with people recovering from COVID-19.

Science at Warp Speed: Medical Research, Publication, and Translation During the COVID-19 Pandemic. *Journal of bioethical inquiry*, 17(4), 555–561.

## Choose your own adventure!

The textbook encourages flexible reading rather than a linear approach. This means that you can read the sections in any order that you prefer, and you can skip over sections that you are already familiar with. You may find some material in multiple chapters (such as an introduction to common symptoms of Long COVID), because we anticipate some readers will only access certain chapters. You can also return to sections you have already read to review the content. All learning and other activities are optional and are designed to support you in translating your new learning into your specific practice context. They can be completed alone or in a group with colleagues. In short, this textbook is really whatever you want to make it!

## Textbook Features

This textbook is hosted on the Pressbooks platform and offers a range of features to enhance your reading experience.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=733#h5p-30>

Another key feature of this textbook is co-authored personas, which are the basis of many reflective and learning activities.

For more information about these personas, please read [this section](#).

## Join Us.

Collaboration is a key feature of OERs, and the editorial team would welcome chapters and other contributions by researchers, clinicians and lived experience experts to build the textbook over time. Chapter authors retain full copyright over their intellectual property, and a formal memorandum of understanding is created to ensure transparency. Generally speaking, prospective authors are asked to submit a brief proposal outlining the topic and objectives of their potential contribution and how it aligns with the broader goals of the resource. Once approved and reviewed by the editorial team, you will likely receive more specific guidelines and instructions on developing your content and peer review requirements. If you want to join us as a co-author, please email us **[covidtextbook@deakin.edu.au](mailto:covidtextbook@deakin.edu.au)**.



# Introduction

*By Danielle Hitch*

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

## Learning Objectives

After reading this chapter and completing the learning activities, you will be able to:

- Reflect upon your own experience of the COVID-19 pandemic and the emerging presence of Long COVID.
- Understand the unique character of Long COVID as a patient-identified syndrome.
- Analyse the apparent gap between healthcare and lived experience expert understanding of Long COVID.
- Examine classifications of Long COVID

symptoms and their potential impact on support and services.

- Explore whether Long COVID should be considered a disability and the practical implications of the ongoing debate on this question.
- Identify 'visible' and 'invisible' Long COVID symptoms and consider their impact on your approach to practice.
- Understand the importance of the wider context surrounding Long COVID to your knowledge and skills when working with people living with this syndrome.

## The first of many waves .....

In the closing days of 2019, news began to emerge from China of a new and initially mysterious respiratory disease.

The first confirmed case was identified on December 8th 2019. By the end of that month, an infectious disease surveillance system based on artificial intelligence raised the first alert about rising case numbers<sup>1</sup>. The virus causing the disease was identified as Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) in the first week of January 2020,

1. Bowles J. (2020) How Canadian AI Start-up BlueDot Spotted Coronavirus Before Anyone Else Had a Clue. Available at: <https://diginomica.com/how-canadian-ai-start-bluedot-spotted-coronavirus-anyone-else-had-clue>.

and the disease it causes was named 'COVID-19' by the World Health Organisation (WHO) on 11 February 2020. By then, cases had been reported across 25 countries <sup>2</sup>, as the infectiousness and **virulence** of COVID-19 became increasingly apparent. On 11th March 2020, case numbers had escalated to the point where WHO declared COVID-19 to be a pandemic <sup>3</sup>.

**For a comprehensive recount of the first 50 days of the COVID-19 pandemic, please read:** Allam, Z (2020). [The First 50 days of COVID-19: A Detailed Chronological Timeline and Extensive Review of Literature Documenting the Pandemic.](#) *Surveying the Covid-19 Pandemic and its Implications*, 1–7.

2. WHO. (2020). Naming the coronavirus disease (COVID-19) and the virus that causes it. Available at [https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-\(covid-2019\)-and-the-virus-that-causes-it](https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid-2019)-and-the-virus-that-causes-it)
3. WHO. (2020). WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. Available at <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020>

## *Reflection (10 minutes)*

**We acknowledge the pandemic has been extremely difficult for many people, and this activity may cause you some discomfort or upset. You do not have to proceed with this reflection if you do not wish to, and please seek support from others if you find it has a negative impact on your health or wellbeing.**

Unlike many of the other illnesses, conditions and disabilities we work with as health professionals and other caregivers, everyone has first-hand experience with COVID-19. Please watch the following video from the World Health Organisation and reflect on how your community responded in the earliest day of the pandemic.

What stands out for you?

With the benefit of hindsight, is there anything that should or could have been done differently?

How did those early days feel for you as an individual?



*One or more interactive elements has been excluded from this version of the text. You can view them online here:*



<https://percollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=4#oembed-1>

Video by [World Health Organisation](#) via YouTube.



For me, the early days of the pandemic passed in a whirlwind of redeployment to front-line duties at work and the complete reorganisation of my duties at home. While the rest of my community was living through the first two (of what would become six) lockdowns, my partner and I were working longer hours than ever as healthcare workers. Our days were blurred together, and we were lucky to have five minutes together as I arrived home and he left for his workplace. In the first six months of the pandemic,

*PPE became a part of everyday life. Photo by Danielle Hitch, [CC BY 4.0](#).*

there were 886 COVID-19 deaths in Australia <sup>4</sup> and 1.12 million deaths globally <sup>5</sup>.

While Australia had been relatively spared, people remained terrified of COVID-19 infection. I often spoke to healthcare workers in tears about their diagnosis, particularly those with pre-existing chronic diseases. I shared their anxieties, as a person with chronic lung disease also caring for elderly and seriously ill relatives. We had all watched the news reports with scenes of overflowing hospitals, and the thought of struggling for breath in a crowded corridor or dying in isolation from loved ones was beyond horrific. However, as winter began to lift and the weather got warmer, optimism started to return and people began to wonder if the worst was finally behind us. The lifting of a 111 day lockdown in October felt like a new beginning, but unbeknownst to many, another wave was beginning to hit our shores.

The following sections, “Why aren’t we getting better?” and “Why is this important?”, are adapted from “[Why the Patient-Made Term ‘Long Covid’ is ... | Wellcome Open Research](#)”, used under [CC BY 4.0](#)

4. Department of Health and Aged Care, Australian Government. (2020). Coronavirus (COVID-19) at a glance – 30 September 2020. Available at <https://www.health.gov.au/resources/publications/coronavirus-covid-19-at-a-glance-30-september-2020>
5. Our World in Data. (2023). Cumulative confirmed COVID-19 deaths by world region. Available at <https://ourworldindata.org/grapher/cumulative-covid-deaths-region>

and “[How and why patients made Long COVID](#)”, used under [CC BY 4.0](#). “Why aren’t we getting better” is licensed under [CC BY 4.0](#) by Danielle Hitch.

## Why aren’t we getting better?

Patients were the first to identify that a significant subset of people was experiencing persistent symptoms and disability following their acute COVID-19 infection. A tweet by a doctor and lived experience expert Elisa Perego on 21st May 2020<sup>6</sup> contains the first recorded use of the term ‘Long COVID’. Patients with these ongoing problems initiated online support groups and began to organise campaigns to raise awareness about the syndrome. Grassroots efforts to raise the alarm about Long COVID emerged in multiple countries, enabled by the reach of the internet and social media platforms. In America, the term ‘long hauler’ emerged, coined by a patient called Amy Watson after the trucking cap she wore on the day she was tested for COVID-19<sup>7</sup>.

6. Perego, E. (2020, 20 May). Twitter. Available at <https://twitter.com/elisaperego78/status/1263172084055838721?s=20>

7. Kate. (2020, Jun 29). Twitter. Available at <https://twitter.com/katemeredithep/status/1277316840453267456/photo/1>

**“Long Covid has a strong claim to be the first illness created through patients finding one another on Twitter: it moved from patients, through various media, to formal clinical and policy channels in just a few months”<sup>8</sup>.**

Without an official name from authorities, Long COVID was rapidly adopted into both vernacular and professional language. By July, it was utilised in World Health Organisation communications and had appeared in the British Medical Journal <sup>9</sup>. Patients were also taking the lead in the embryonic research on the syndrome, with patient-led surveys playing a crucial

role in the world’s initial understanding of what we were all dealing with <sup>10</sup>. While there are many past examples of patients (henceforth known as lived experience experts) challenging the knowledge and practice of formalised healthcare, Long COVID is a rare example of them taking the lead. This raises some interesting questions about the nature of expertise, which is a recurring theme throughout this book.

8. Callard, F., & Perego, E. (2021). How and why patients made Long COVID. *Social Science & Medicine*, 268(1), 113426.

9. Mahase, E. (2020). COVID-19: What do we know about "long covid"? *British Medical Journal*, 370(7), m2815-m2815.

10. McCorkell, L., Assaf, G., Davis, H., Wei, H., & Akrami, A. (2021). Patient-Led Research Collaborative: embedding patients in the Long COVID narrative. *PAIN Reports*, 6(1), e913,

An ongoing area of contention and debate between healthcare and lived experience experts is the classification of COVID-19 infection as mild, moderate or severe. The United States National Institute of Health considers oxygen saturation as measured by pulse oximetry (SpO<sub>2</sub>) to be the key

**“How scientists engage with knowledge about new diseases affects how meaning about a disease accrues, how terminology solidifies, and which evidence is prioritized”<sup>11</sup>**

parameter in their clinical classification of COVID-19 infection severity, which ranges from asymptomatic to critical<sup>12</sup>. However, other classification approaches proposed are based on biomarkers such as D-Dimer<sup>13</sup>, Computed Tomography (CT) visual quantitative analysis<sup>14</sup> and immuno-phenotyping<sup>15</sup>.

11. Callard, F., & Perego, E. (2021). How and why patients made Long COVID. *Social Science & Medicine*, 268(1), 113426.
12. National Institute of Health. (2023, Mar 6). Clinical spectrum of SARS-CoV-2 infection. Available at [www.covid19treatmentguidelines.nih.gov/overview/clinical-spectrum/](https://www.covid19treatmentguidelines.nih.gov/overview/clinical-spectrum/)
13. Yao, Y., Cao, J., Wang, Q., Shi, Q., Liu, K., Luo, K., Luo, Z., Chen, X., Chen, S., Yu, K., Huang, Z., & Hu, B. (2020). D-dimer as a biomarker for disease severity and mortality in COVID-19 patients: a case-control study. *Journal of Intensive Care*, 8, Article 49.
14. Li, K., Fang, Y., Li, W., Pan, C., Qin, P., Zhong, Y., Liu, X., Huang, M., Liao, Y., & Li, S. (2020). CT image visual quantitative evaluation and clinical classification of coronavirus disease (COVID-19). *European Radiology*, 30, 4407-4416.
15. Mueller, Y.M., Schrama, T.J., Ruijten, R. et al. (2022).

However, as noted in the following blog post, mild symptoms are always mild.

## Learning Activity (25 minutes)

### Part A

The existing classification systems for COVID-19 infection are mostly based on the acute phase of infection. Still, there is not necessarily a linear link between the severity of the initial illness and those experienced in the post-acute phase.

Read [Coronavirus FAQ: Remind me, how do you define mild, moderate and severe COVID?](#)

- How would you describe the apparent gap between how healthcare and lived experience experts characterise the severity of their COVID-19 infection? Use the Padlet below to comment on the apparent gap between how healthcare and lived experience experts characterise the severity of their COVID-19 infection. What implications could these different perceptions have for the issues such as the development of new

Stratification of hospitalized COVID-19 patients into clinical severity progression groups by immuno-phenotyping and machine learning. Nature Communications, 13, 915.

treatments and therapies, and/or patient engagement?

- You can also comment on other posts, but remember. **This is a public board, and please do not include any identifying information.** This padlet is best viewed in full-screen mode.



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=4#h5p-22>

## Part B

An integrative classification for defining Long COVID symptoms has been developed, which describes the status of symptoms over time.

Read Section 4 of [Defining Post-COVID symptoms \(Post-Acute COVID, Long COVID, Persistent Post-COVID\): An integrative classification](#). The authors propose three models based on time reference points linked to the need for hospitalisation and the presence of symptoms.

- Reflect on the benefits and disadvantages of these models. What could a classification system based on time reference points enable or support

in practice? How well do you think these models of classification align with the perspective of lived experience experts?

By August 2020, the inverted commas around ‘Long COVID’ began to disappear in media accounts which might be interpreted as a sign of growing acceptance for the term. However, three years later, they still reappear regularly in the literature. A challenge for everyone in this field is the instability of Long COVID definitions and descriptions. There are a huge number of potential presentations, and so the scope and boundaries of what ‘is’ and what ‘isn’t’ Long COVID are extremely fuzzy. While some criticise ‘Long COVID’ as being too vague and all-encompassing, lived experience experts and others argue this accurately reflects the uncertainty that pervades this area. The editors of this book agree with Callard and Perego<sup>16</sup> that lived experience experts with diverse experiences and recovery trajectories must be included in the ongoing deliberations about the terminology and definitions used for Long COVID.

## **A ‘mass disabling’ event?**

In response to a TikTok about the long-term effects of COVID-19 infection, disability advocate Imani Barbarin asserted, “I can’t stress this to you all enough, but Covid-19 is a mass disabling event. People are becoming disabled because of Covid19. This society, America in particular, is not prepared for it—at all.”

16. Callard, F., & Perego, E. (2021). How and why patients made Long COVID. *Social Science & Medicine*, 268(1), 113426.



[@crutches\\_and\\_spice](#)

[#stitch](#) with @ramdanielle things will never be the same. Never. You may now become who you thought was disposable. [#quarantine](#) [#covid19](#)

[🎵 original sound – Crutches&Spice 🧠](#):

Video by @crutches\_and\_spice via TikTok.

### **Words Matter**

*I'd like to take a moment here to acknowledge that people with Long COVID use several different terms to describe their experiences. The word 'recovery' was chosen in the title of this book to reflect an improving trend in health and wellbeing over time. It was also chosen from the perspective of 'personal recovery' which entails being "able to create and live a meaningful life and contribute to your community" regardless of the presence of chronic or complex conditions<sup>17</sup>. However, I acknowledge that not all people with Long COVID feel they are recovering and there are aspects of their health, wellbeing, experience and identify that may never be the same again. Referring to something as 'normal' or 'typical' is also very triggering for some people, who point out (quite rightly) that we don't yet know what 'normal' is for*

17. healthdirect. (2023) Recovery and mental health. Available at <https://www.healthdirect.gov.au/mental-health-recovery>

*Long COVID. Other potential options (such as managing, surviving and living with) were considered but may also be problematic in other ways. The use of the word 'recovery' throughout this book is not intended to impose a particular perspective or language on the lived experience of people with Long COVID. It is one of many ways to describe the syndrome, and health professionals and other caregivers should use the terminology preferred by each individual person.*

*Not everyone characterises their Long COVID as a disability. This term carries centuries of stigma, discrimination and stereotyping, and tends to focus on what people can't do (rather than what they can). People may also choose not to identify as 'disabled' because they don't want to be defined by their health status. Alternatively, people may choose to take on this identity as a means of advocating for their needs or as a strategic decision to gain access to the services and supports they need. An alternative is to call Long COVID a condition, illness or disease, and there is now growing acceptance of the reality of its impact on health and wellbeing. While healthcare professionals refer to Long COVID as a syndrome, this is not a term the general community would choose. The section that follows explores the framing of Long COVID as a disability, and the differing perspectives this offers our understanding of the syndrome. This is not to say that all people with Long COVID must identify as having a*

*disability – only the person experiencing it gets to decide what part (if any) Long COVID plays in their personal identity.*

There are three main models of disability – medical, biopsychosocial and social. These models differ in their perspectives on the causes of disability, their focus and the intervention they support.

### *The Medical Model of Disability*

The medical model of health is present in all areas of modern healthcare. While it is most usually associated with medicine, it is also adopted by some other health professions. This model prioritises the diagnosis and treatment of diseases and injuries through interventions, such as medication, surgery, and other procedures. The medical model defines health as the absence of disease or illness, and therefore the goal is to cure or effectively manage conditions by reducing or eliminating symptoms. Health professionals who adopt this perspective utilise objective tests and assessments to guide their interventions and often specialise in a specific body system or structure.

In this model, disability is caused by one (or more health) impairments, which cause a lack of function according to personal and/or other norms. In Long COVID, the medical model is primarily focused on understanding and relieving the various symptoms of this syndrome, which requires the knowledge and experience of multiple medical and other healthcare specialties.

The medical model has been the foundation of the huge advances made in healthcare in recent centuries, and practice from this perspective can undoubtedly have a positive impact on patients. However, the medical model has also been criticized for providing a narrow definition of disability and for not considering the impact of social and environmental factors<sup>18</sup>.

### *The Biopsychosocial Model of Disability*

**“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”<sup>19</sup>.**

The biopsychosocial model of health is a more recent development that asserts that health and illness arise from the complex interactions between biological, psychological, and social factors. The International Classification of

Functioning, Disability and Health (ICF) is a biopsychosocial model developed by the World Health Organization (WHO) that provides a framework for classifying disability which is intended for use across multiple disciplines and sectors<sup>20</sup>. The

18. Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine*, 8, 134–138.
19. International Health Conference. (2002). Constitution of the World Health Organization. 1946. *Bulletin of the World Health Organization*, 80 (12), 983-984.
20. Forhan, M. (2009) An analysis of disability models and the application of the ICF to obesity, *Disability and Rehabilitation*, 31(16), 1382-1388.

structure of this textbook is founded on the ICF (see below); however, we acknowledge this is not the only way of considering disability in Long COVID.

In this model, health professionals work with patients to identify and address physical symptoms, psychological factors and social issues contributing to their disability. This means inter-related influences (for example, their social support network, stress levels, lifestyle habits, socio-economic status, personal perspectives of their illness or disability, etc.) are integrated into assessment and treatment, in addition to presenting medical or biological factors. The biopsychosocial model supports a multidisciplinary approach to care and management because multiple health professions have expertise in the many potential influences on health and illness. In Long COVID, the biopsychosocial model looks at a wider range of potential influences in the patient's personal context, including the broader societal impact of the pandemic.

The biopsychosocial model is broadly seen as building on the medical model and has become widely accepted and practised in modern healthcare. However, it has also been criticised for being vague and lacking clarity about the interactions between biological, psychological, and social factors<sup>21</sup>. The complexity of the model also makes it challenging to implement into practice, and some believe culture and spirituality are not given sufficient attention<sup>22</sup>.

21. Bolton, D., & Gillett, G. (2019). The Biopsychosocial Model 40 Years On. In: *The Biopsychosocial Model of Health and Disease*. Palgrave Pivot/
22. Lehman, B.J., David, D.M., & Gruber, J.A. (2017). Rethinking the biopsychosocial model of health: Understanding health as a dynamic system. *Social and Personality Psychology Compass*, 11(8), 11:e12328.

## *The Social Model of Disability*

People with disability originally developed the social model of health. It focuses on the role of social and environmental factors in causing health and illness. In this model, a person is disabled by their social and cultural environment rather than their impairment. Therefore, in contrast to the other models, the social model of disability targets the root causes of health inequity by advocating for social justice and promoting policies and actions to address the underlying social determinants of health. In Long COVID, the social model seeks to switch the focus from the 'deficits' of people with this syndrome to the responsibility of the broader community (including those in positions of power) to be inclusive of their needs.

Please watch the following video for an overview of this and other models.



*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=4#oembed-2>*

Video by [Enabled Futures](#), [CC BY 3.0](#) via YouTube.

## Learning Activity (20 mins)

All three of these models have a presence in the healthcare system and will be represented in the content of this textbook. They are, therefore, not necessarily incompatible, as noted by Rudnick<sup>23</sup>.

**“The dichotomy between the medical model of disability and the social model of disability is false, as these models are neither mutually exclusive nor jointly exhaustive. Disability can be caused by both health impairments and social circumstances, and other factors, such as personal and environmental factors, can cause disability” (p.1).**

The primary (but not only) differences between the models are due to their scope or focus and how they define disability.

### PART A

Use a copy of the table below ([Downloadable Table Template](#)) to reflect on the advantages and disadvantages of each model, specifically in relation to Long COVID.

23. Rudnick, A. (2017). The medical versus the social model of disability: A false dichotomy. *Physical and Medical Rehabilitation Research*, 2, doi: 10.15761/PMRR.1000157

Model	Medical Model of Long COVID	Biopsychosocial Model of Long COVID	Social Model of Long COVID
Advantages			
Disadvantages			
Relationship to other models			

PART B

There may be elements of your practice that align with more than one model, and the scope of your work will be heavily influenced by the service system in which you work. Which (if any) of these models resonates with your work with people recovering from COVID-19? Reflect on or discuss their presence (or absence) in your work.

Recognition of Long COVID as a disability (or not) has serious implications and impacts on the daily lives of people with this syndrome. Identification as a person with a recognised disability is a crucial criterion for accessing support services, resources and accommodations. Many countries have legislative instruments, such as Disability Discrimination Acts, that prohibit discrimination and promote inclusion and accessibility in everyday life for people with disability. Currently,

**“I was actually thrown out of a doctor’s office .... [they said] ‘it’s a made-up illness’, so I was wasting her time” (F, 30-49 years)**



the United States of America is one of the few jurisdictions that officially recognises Long COVID as a disability and provides [guidance around inclusion and accessibility](#). However, the legal status of the syndrome is far from settled in other countries meaning that access to formal support and services varies significantly depending on where you live. As the highlighted quote from one of our research participants shows, lack of formal recognition can also be a cause of stigma and discrimination, which is a known psychosocial contributor to poorer health experiences and outcomes.

## Learning Activity (10 mins)

Read the following analysis from the British Medical Journal, which discusses some potential consequences of Long COVID being recognised as a disability.

### [Long COVID and disability: A brave new world.](#)

- Is Long COVID recognised as a disability and/or specific condition in your jurisdiction?
- What supports and services can and can't people with Long COVID access in your community?

Disability legislation often reflects the tenants of

the United Nations Convention on the Rights of Persons with Disability, which has been signed and ratified by most (but not all nations). Click [here](#) to learn more about this important human rights instrument.

## Now you see me .....

Another important dimension of COVID-19 recovery and Long COVID is the ‘invisibility’ of many symptoms. Use the following activity to reflect on what you can see and what you can’t in your own practice. This may differ depending on your scope of practice – in other words, what you are ‘looking for’ as a health professional.

### Learning Activity (10 mins)

You have been provided with a list of the most common symptoms reported by people with Long COVID. Please remember these are only the most frequently described – Long COVID can manifest in a huge variety of signs and symptoms, and you will need to develop an individualised symptom profile with each person you work with. Consider each in turn and move

the card into the box that best describes how you would identify each symptom as a health professional. Reflect on how much you can and cannot see about the symptoms your patients are experiencing.

#### Instructions

- You can only put each symptom in one box.
- 'Direct observation' includes objective tests/evaluation and your observations in clinical/home/community environments.
- 'Cannot be directly observed' includes symptoms only accessible by patient reports or patient-rated outcome measures.
- ADL stands for activities of daily living
- This activity is best viewed in full-screen mode.
- **Do not** press 'check' – this activity has no right or wrong answers.

Reflect on how much you can and cannot see about the symptoms your patients are experiencing.



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=4#h5p-23>

People with Long COVID often comment on the additional difficulties they encounter when their disability is not obvious

or directly observable. These challenges are well-known in the broader disability community, as highlighted in the following video.



*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=4#oembed-3>*

Video by [Australian Human Rights Commission](#) via YouTube.

## Amplified ‘isms.

The following section is adapted from “[Long COVID: Sustained and multiplied disadvantage](#)” used under [CC BY 4.0](#) by Evelyne Leeuw, Aryati Yashadhana and Danielle Hitch.

When diversity is not represented in lived experience expertise, patients are subjected to epistemic injustice<sup>24</sup> where the knowledge about Long COVID is skewed by excluding marginalised groups. Culturally and linguistically diverse (CALD) patients and those living with disability are particularly at risk of having their symptoms dismissed or underplayed

24. Fricker, M. (2011). *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press.

<sup>25</sup>. The voices of marginalised people (including those living with chronic conditions) remain mostly unheard despite the compounding impact of the pandemic and Long COVID on the disadvantages and challenges they face every day.

While the impairment and disability caused by Long COVID can also be mostly invisible, the pandemic has bought long-held attitudes towards a range of other aspects of disadvantage into the light. Ableism, sexism, racism and ageism have all been amplified during the COVID-19 pandemic, and their suppressive effects on diversity have the potential to sabotage growing international efforts to manage Long COVID effectively. Several groups and populations have also been disproportionately affected by the COVID-19 pandemic. They may be considered at risk from a medical perspective and/or from the perspective of their opportunities to function and participate in the community.<sup>26</sup> From an equity perspective, the over-representation of chronic conditions among disadvantaged (and often racialised) populations (e.g., Indigenous Australians)<sup>27</sup> increases the risk of both acute COVID-19 severity and long COVID. The infection risk for severe acute respiratory syndrome coronavirus 2

25. Yong E. 2020. Long-Haulers Are Redefining COVID-19. The Atlantic. Available from:<https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/>

26. Cardona, B. (2021). The pitfalls of personalization rhetoric in time of health crisis: COVID-19 pandemic and cracks on neoliberal ideologies. *Health Promotion International*, 36, 714–721.

27. Yashadhana A, Pollard-Wharton N, Zwi AB, Biles B. Indigenous Australians at increased risk of COVID-19 due to existing health and socioeconomic inequities. *Lancet Reg Health West Pac* 2020; 1: 100007.

(SARS-CoV-2) is associated with age, immune status, and certain pre-existing non-communicable diseases such as obesity, asthma etc. One of the few predictive models available for long COVID has found associations with age, body mass index, female sex and the number of symptoms experienced within the first seven days of infection<sup>28</sup>. Each of these factors is already profoundly driven by the social determinants of health and health inequity.

Extant literature on the distribution and inequitable nature of the pandemic has mostly focused on infections, case numbers and vaccination rates. But

**“The pandemic will be with us for a long time; we need to engage with its inequities”<sup>29</sup>**

scholars and commentators have increasingly identified and advocated critical fault lines in “glocal” (where global and local meet) society<sup>30 31</sup>. The recognition of “living with COVID-19” in a “new normal” only peripherally acknowledges continuing patterns of inequity and vulnerability, both in terms of

28. Sudre CH, Murray B, Varsavsky T, et al. Attributes and predictors of long COVID. *Nat Med* 2021; 27: 626–631.
29. Leeuw, E., Yashadhana, A., & Hitch, D. (2022). Long COVID: sustained and multiplied disadvantage. *Medical Journal of Australia*, 216(5), 222-224.
30. Bambra C, Lynch J. *The unequal pandemic: COVID-19 and health inequalities*. Policy Press, 2021.
31. Permanand G, Kirkby V, McKee M. Take action at all levels of society to fix the fractures that left so many people vulnerable to the pandemic. In: McKee M, editor. *Drawing light from the pandemic: a new strategy for health and sustainable development*. Pan-European Commission on Health and Sustainable Development; 2021.

acquiring infection as well as maintaining immunity (either through vaccination or recovery). These patterns produce a sustained but inequitable distributed wave of post-COVID-19 social and health impacts; in short, the disadvantaged continue to suffer more and longer.

The enduring effects of long COVID in groups that already experience disadvantage and inequality will also make livelihoods more perilous. The detrimental health effects of what is called the “precariat” — “gig economy” workers (ride-share drivers, food delivery riders, workers in precarious jobs, hosts of short-term rentals etc.), who are led to believe that they will achieve greater choice and more freedom in their livelihoods at the cost of appropriate social protections such as insurance, unemployment security, and old-age investment — have been identified <sup>32</sup>. The disadvantage stemming from these failures in the current (absence of the) social contract is only exacerbated by compounding barriers to living one’s life to the full. It may contribute to longer-term destabilising and incapacitating social, economic and health consequences in future stages of life with COVID-19. For a social justice-driven recovery in a post-COVID-19 era, it is imperative that two things are taken on board by health professionals and other caregivers at all levels and across all jurisdictions:

- **“It ain’t over for some until it’s over for all.”** Building back better must embrace the full spectrum of disease emergence, spread, control, follow-up, and healthcare delivery in every stage of prevention, management and investment in care, explicitly including Long COVID.

32. Muntaner C. Digital platforms, the gig economy, precarious employment, and the invisible hand of social class. *Int J Health Serv* 2018; 48: 597–600.

- Planning for this must involve **not just rhetorical allusions to priority populations** without meaningful operational action. Critical intersectionality creates pockets of deep and irreconcilable injustice and health inequity if public and non-government organisations maintain a siloed mantra of priorities.

A number of things need to happen to achieve these aspirations. Definitions and descriptions of Long COVID employed by services must be co-created with lived experience experts to enable consistent and adequate clinical diagnosis, management and social responses. National and International Long COVID data must be disaggregated by equity indicators such as socioeconomic status, geography, and ethnicity to provide quality evidence to build action. The PROGRESS-Plus protocol is a helpful tool to assemble and communicate the dimensions of disadvantage that must be addressed<sup>33</sup>. Health professionals and other caregivers must also engage and collaborate with equity-seeking populations and communities most affected to understand lived realities and potential solutions. Developing policy responses to Long COVID is also a key aspect of an effective health and social response<sup>34</sup>, and could extend beyond the health sector to encompass

33. Oliver S, Kavanagh J, Caird J, et al. Health promotion, inequalities and young people's health: a systematic review of research. London: EPPI-Centre, 2008. <https://eppi.ioe.ac.uk/cms/Portals/0/PDF%20reviews%20and%20summaries/Inequalities%20Young%20People%20R2008Oliver.pdf?ver=2010-12-22-123934-167> (viewed Oct 2021).
34. Hensher M, Angeles MR, de Graaf B, et al. Managing the long-term health consequences of COVID-19 in Australia. Deeble Institute, 2021. <https://apo.org.au/sites/default/files/resource-files/2021-05/apo-nid312413.pdf> (viewed Oct 2021).



structural inequities, such as housing availability and affordability, lack of adequate social protection, and marginalisation. And finally, dealing with the fall-out of the pandemic on all fronts will require a tangible commitment to deliver across sectors and for everyone.

### Learning Activity (30 mins)

Read the persona of [Gayle Smith](#). Her experience of Long COVID features aspects of intersectionality – interconnected and interdependent aspects of her identity which create overlapping and potentially compounding systems of discrimination or disadvantage. The PROGRESS-Plus Framework lists a range of characteristics that may have an impact on health, well-being or outcomes.

Use a copy of the table below ([Downloadable Table Template](#)) to identify the aspects of Gayle’s identity and circumstances which might influence her lived experience of Long COVID. Discuss and note down the effects they may have, both positive and/or negative.

<b>Characteristic / Circumstance</b>	<b>Gayle Smith</b>	<b>Potential Positive Effects</b>	<b>Potential Negative Effects</b>
Place of residence (rural/urban, country/state, housing characteristics)			
Ethnicity / Ethnic background			
Occupation (professional, skilled, unskilled, unemployed, retired)			
Gender (male, female, transgender, non-binary, other)			
Religion / Religious background			
Education (Years in education/ level attained / School type)			
Social Capital (Neighborhood / community / family support)			
Socio-Economic Position (Income, benefits/ welfare)			
Age group			

Disability (physical, cognitive or emotional disability)			
Sexual orientation (Heterosexual, gay, lesbian, bisexual, other)			
Other vulnerabilities (School non-attenders, contact with the criminal justice system, experiences of abuse or trauma, etc.).			

- Reflect on her characteristics and circumstances as a whole. Which would be most relevant to your work with Gayle, and how would you acknowledge or address them in your work with her?

## Conclusion.

**“In the making of Long COVID, conventional hierarchies of evidence and normative routes for scientific dissemination were frequently disrupted”**<sup>35</sup>

The content of this chapter sets the tone and provides some context for the rest of this textbook, which takes an explicitly patient-centred perspective. Equal value and presence are given throughout this resource to professional and patient knowledge because we agree with Callard and Perego<sup>36</sup> that “conventional

*health actors should include these contributions within formal scientific practices.”* Our stance reflects the strong commitment of the editorial team to inclusion and equity for everyone in our community.

Developing an understanding of the broader context of the pandemic, disability, and disadvantage provides an essential foundation for health professionals and other caregivers. The challenges associated with managing Long COVID extend far beyond the health needs of individual patients, and their lived experience is inextricably entwined with a huge range of **environmental factors** and **social determinants**. Significant equity issues are associated with Long COVID, and this chapter has barely scratched the surface. These issues and effective

35. Callard, F., & Perego, E. (2021). How and why patients made Long Covid. *Social science & medicine*, 268, 113426.

36. Callard, F., & Perego, E. (2021). How and why patients made Long COVID. *Social science & medicine*, 268, 113426.

ways to promote justice and equity will be explored in more detail later in this textbook.

## For More Information

The following links will provide you with additional general information about Long COVID from creditable sources. The listings are not exhaustive, and you are encouraged to seek out locally relevant information for your community.

- **The broader context of patient activism around Long COVID**
  - McClymont, G. (2021). [The Role of Patients and Patient Activism in the Development of Long COVID Policy](https://doi.org/10.17863/CAM.75505). *Cambridge Journal of Science and Policy*, 2(1), <https://doi.org/10.17863/CAM.75505>.
  - Lincoln, M. (2021). Necrosecurity, Immunosupremacy, and Survivorship in the Political Imagination of COVID-19. *Open Anthropological Research*, 1(1), 46-59. <https://doi.org/10.1515/opan-2020-0104>
- **Lived experience stories from people with Long COVID**
  - <https://www.c19recoveryawareness.com/>
  - <https://www.longcovidssos.org/film>

Please consider providing us with some feedback via the following satisfaction survey to help us ensure this textbook meets the needs of all readers: [Brief Feedback Survey – Introduction Chapter](#). If you have any additional feedback, suggestions or recommendations for improvement to this chapter, please email the editors at **covidtextbook@deakin.edu.au**.

## References

# PART I

# BODY SYSTEMS AND STRUCTURES

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

Body Functions and Body Structures are two of the categories of the International Classification of Function (ICF). Body Functions include “the physiological functions of body systems (including psychological functions”<sup>1</sup>. Body Structures include “anatomical parts of the body such as organs, limbs and their components”<sup>2</sup>.

The eight ICF chapter headings for body functions are listed below, and each contains a list of components (see [here](#) for more information).

- Mental functions
- Sensory functions and pain
- Voice and speech functions

1. Centres for Disease Control and Prevention. (2010). The ICF: An overview. Available at [www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](http://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)
2. Centres for Disease Control and Prevention. (2010). The ICF: An overview. Available at [www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](http://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)

- Functions of the cardiovascular, haematological, immunological and respiratory systems
- Functions of the digestive, metabolic, and endocrine systems
- Genitourinary and reproductive functions
- Neuromusculoskeletal and movement-related functions
- Functions of the skin and related structures

The eight ICF chapter headings for body structures are listed below and also contain a list of components (see [here](#) for more information).

- Structure of the nervous system
- The eye, ear and related structures
- Structures involved in voice and speech
- Structure of the cardiovascular, immunological and respiratory systems
- Structures related to the digestive, metabolic and endocrine systems
- Structure related to genitourinary and reproductive systems
- Structures related to movement
- Skin and related structures.



# 1. What is Long COVID?

*By Danielle Hitch*

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

## Learning Objectives

After reading this chapter and completing the learning activities, you will be able to:

- Reflect upon your current knowledge about Long COVID, and identify areas you wish to develop.
- Understand how Long COVID is currently described and defined.
- Identify the most common symptoms of Long COVID.
- Analyse a sub-phenotype presenting in an individual with Long COVID.
- Examine the lived experience of Long COVID

from the patient's perspective.

- Create a patient journey map for an individual with Long COVID.
- Identify further resources to support your ongoing development in this area.

## Introduction

Long COVID affects millions of people worldwide, and its impact on individuals, healthcare systems, economies and broader society is still not fully understood. This chapter aims to provide a comprehensive overview of Long COVID, including its characteristics, symptoms, and risk and protective factors. We will also provide an overview of the current evidence in this field and explore the lived experience of Long COVID from the patient's perspective. There is a huge amount to learn about Long COVID, and this chapter will provide you with a launching pad for your further learning in this area.

## What do you already know about Long COVID?

There is growing recognition of Long COVID, as the longer-term effects of **COVID-19** infection become more apparent. It's likely you already have at least some understanding of this condition, even if you have not studied it or treated people that experience its symptoms. Before you begin reading this

chapter, we would like you to reflect on what you know already – this is the foundation you will build upon.

## Reflection (10 mins)

Use the Padlet below to post what you know about Long COVID. What are the symptoms? What issues can it cause people? What causes Long COVID, and what treatments are available? You can also comment on other posts, but remember – **This is a public board, and please do not include any identifying information.**



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#h5p-13>

Have you identified any gaps in your knowledge? If so, note them down and see if this chapter helps you develop your knowledge.

As an introduction to this chapter, take a couple of minutes to watch the following video. It was co-produced with people

experiencing Long COVID and included the information they want people in the broader community to know about the syndrome.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#oembed-1>

While most people fully recover from acute **COVID-19** infection, some continue to experience symptoms that persist for months or years. There are many names for these symptoms – Post-Acute COVID19 Syndrome (PACS), Post-Acute COVID19 Condition (PACC), Chronic COVID Syndrome (CCS), Long-haul COVID, Persistent Post-COVID19 Syndrome (PPCS), and Long-term effects of COVID (LTEC)<sup>1 2</sup>. As stated in the introduction chapter, the term **Long COVID** is used in this textbook in

1. Fernández-de-las-Peñas, C. (2022). Long COVID: Current definition. *Infection*, 50, 285–286.
2. Soriano, J. B., Murthy, S., Marshall, J. C., Relan, P., & Diaz, J. V. (2022). A clinical case definition of post-COVID-19 condition by a Delphi consensus. *The Lancet Infectious Diseases*, 22(4), e102-e107.

recognition of its identification by consumers and common use in the community.<sup>3 4 5 6 7</sup>

## Definitions and descriptions of Long COVID.

Several definitions and descriptions of Long COVID are available internationally, most of which are broadly similar. Five

3. World Health Organisation (WHO). (2021). A clinical case definition of post-COVID-19 condition by a Delphi consensus. Geneva: WHO.
4. Enter your footnote content here. National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), & Royal College of General Practitioners (RCGP). (2022). COVID-19 rapid guideline: Managing the long-term effects of COVID-19. Version 1.14. London: NICE, SIGN, RCGP.
5. Centers for Disease Control and Prevention. Long COVID or Post-COVID Conditions 2022 [Available from: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.]
6. Stephenson, T., Allin, B., Nugawela, M. D., Rojas, N., Dalrymple, E., Pereira, S. P., ... & CLoCk Consortium. (2022). Long COVID (post-COVID-19 condition) in children: a modified Delphi process. *Archives of Disease in Childhood*, 107(7), 674-680.
7. Fernández-de-las-Peñas, C., Palacios-Ceña, D., Gómez-Mayordomo, V., Cuadrado, M.L., & Florencio, L.L. (2021). Defining Post-COVID Symptoms (Post-Acute COVID, Long COVID, Persistent Post-COVID): An Integrative Classification. *International Journal of Environmental Research and Public Health*, 18, 2621.

of these descriptions are presented in the boxes below for your review.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#h5p-10>

## Learning Activity (20 mins)

Using a copy of the table below ([Downloadable Table Template](#)), identify the similarities and differences between the definitions and descriptions in the information wall.

	W HO	NI CE	C DC	Great Ormond Street	Fernández-de-las-Peñas et al.	
Evidence of COVID-19						
The time point for identification						
Trajectory of symptoms						
Impact on daily life						

Do the differences between the definitions and descriptions matter to your clinical work? Discuss or reflect upon why or why not.

## The impact of Long COVID on the human body.

Body  
Functions &  
Body Structure

This section will provide you with general information about the etiology (causes), diagnosis (symptoms), course (recovery) and prognosis (outlook) of Long COVID. Further detail about the syndrome's impact on specific body functions and body structures will be available in future chapters of this book.

## *What causes Long COVID?*

The short answer is Long COVID is caused by the **SARS-CoV-2** virus. Like most aspects of COVID recovery, it's not as simple as that... Not everyone with an acute COVID-19 infection goes on to have Long COVID. While prevalence estimates vary, many fall within 10%-15% of COVID-19 infections<sup>8</sup>. Currently, we can't be certain why this amount of people with acute COVID-19 infection experience persistent symptoms long after most others have recovered. However, there are five general hypotheses about potential contributors to Long COVID. None of these factors are considered to be the 'sole' cause of Long COVID. Rather, it is likely that they interact in fluid and complex ways.

### Possible Causes of Long COVID

#### **Viral Persistence:**

- Studies suggest that viral persistence may be

8. Ayoubkhani, D., Pawelek, P., & Gaughan, C. (2021). Technical article: Updated estimates of the prevalence of post-acute symptoms among people with coronavirus (COVID-19) in the UK: 26 April 2020 to 1 August 2021. London: Office of National Statistics.



caused by the immune system failing to completely clear the virus or by mild persistent infection. Some organs seem particularly susceptible to becoming viral reservoirs, including the lungs<sup>9</sup>, the intestines<sup>10</sup> and the olfactory mucosa<sup>11</sup>. More research is needed to fully understand how viral persistence occurs and its relationship to Long COVID. Better knowledge in this area could lead to the effective use of antiviral therapies and immunomodulatory treatments, or the repurposing of existing drugs.

**Autoimmune responses:**

- These responses occur when a person's

9. Caniego-Casas, T., Martínez-García, L., Alonso-Riaño, M., Pizarro, D., Carretero-Barrio, I., Martínez-de-Castro, N., ... & Palacios, J. (2022). RNA SARS-CoV-2 persistence in the lung of severe COVID-19 patients: a case series of autopsies. *Frontiers in microbiology*, 13, 824967.
10. Swank, Z., Senussi, Y., Manickas-Hill, Z., Yu, X. G., Li, J. Z., Alter, G., & Walt, D. R. (2023). Persistent Circulating Severe Acute Respiratory Syndrome Coronavirus 2 Spike Is Associated With Post-acute Coronavirus Disease 2019 Sequelae. *Clinical infectious diseases*, 76(3), e487–e490.
11. de Melo, G. D., Lazarini, F., Levallois, S., Hautefort, C., Michel, V., Larrous, F., ... Lledo, P. M. (2021). COVID-19-related anosmia is associated with viral persistence and inflammation in human olfactory epithelium and brain infection in hamsters. *Science translational medicine*, 13(596), eabf8396.

immune system overreacts to the virus or mistakenly attacks their own body. This leads to persistent inflammation and damage to healthy tissues, which can result in a wide range of chronic diseases, several share some similar symptoms with Long COVID (such as rheumatoid arthritis, chronic fatigue syndrome and lupus). While patients with pre-existing autoimmune disorders are considered at higher risk of COVID-19 infection in the first place<sup>12</sup>, there is also evidence to suggest there is an increased risk of developing a range of autoimmune diseases following COVID-19 infection<sup>13</sup>.

#### **Cardiovascular complications:**

- COVID-19 can cause both primary and secondary damage to blood vessels, resulting in reduced blood flow to vital organs<sup>14</sup>. The

12. Akiyama, S., Hamdeh, S., Micic, D., & Sakuraba, A. (2021). Prevalence and clinical outcomes of COVID-19 in patients with autoimmune diseases: a systematic review and meta-analysis. *Annals of the Rheumatic Diseases*, 80, 384-391.
13. Chang, R., Chen, T. Y. T., Wang, S. I., Hung, Y. M., Chen, H. Y., & Wei, C. C. J. (2023). Risk of autoimmune diseases in patients with COVID-19: A retrospective cohort study. *EClinicalMedicine*, 56, 101783.
14. Kondo, M., & Yamanaka, K. (2021). Possible HSP reactivation post-COVID-19 vaccination and booster. *Clinical Case Reports*, 9, e05032.

development of 'micro-clots' post-infection has received a lot of attention (some of which is contentious), given their potential to cause hypoxia, oxidative stress and inflammation<sup>15</sup>. The inflammatory response appears to be the main cause of acute cardiovascular complications in COVID-19<sup>16</sup>, which can include myocardial infarction, myocarditis, arrhythmia, heart failure, shock, and venous thromboembolisms / pulmonary embolisms<sup>17</sup>.

### **Neurological Damage:**

- Recent studies indicate the COVID-19 virus can cross the blood-brain barrier, potentially causing demyelination or axonal damage<sup>18</sup>. Regardless of

15. Willyard, C. (2022). Could tiny blood clots cause long COVID's puzzling symptoms? *Nature*, 608, 662-664.
16. Grant, J.K., Vincent, L., Ebner, B., Hurwitz, B.E., Alcaide, M.L., & Martinez, C. (2020). Early Insights into COVID-19 in Persons Living with HIV and Cardiovascular Manifestations. *Journal of AIDS and HIV Treatment*, 2(2): 68-74.
17. Dou, Q., Wei, X., Zhou, K., Yang, S., & Jia, P. (2020). Cardiovascular manifestations and mechanisms in patients with COVID-19. *Trends in Endocrinology & Metabolism*, 31(12), 893-904.
18. Desforges, M., Le Coupanec, A., Dubeau, P., Bourgouin, A., Lajoie, L., Dubé, M., & Talbot, P. J. (2019). Human Coronaviruses and Other Respiratory Viruses: Underestimated Opportunistic Pathogens of the Central Nervous System? *Viruses*, 12(1), 14.

the need for hospitalisation in the acute phase of COVID-19, patients are at higher risk of a wide range of neurological problems for at least 12 months following infection. These problems include stroke, cognition and memory disorders, peripheral nervous system disorders, migraine, epilepsy, extrapyramidal and movement disorders, mental health disorders, musculoskeletal disorders, sensory disorders, Guillain–Barré syndrome, and encephalitis or encephalopathy<sup>19</sup>. Structural damage can also occur to neurological organs and tissues, with persistent white matter changes found in COVID-19 patients one year after their infection<sup>20</sup>.

#### **Mental Health:**

- The anxiety caused by COVID-19 infection may be compounded by the general distress experienced by the community from the broader impacts of the pandemic. Both sources of stress may have long-lasting effects on mental health, which can contribute to Long COVID symptoms. Mental health symptoms are commonly reported by people with Long COVID, including anxiety,

19. Xu, E., Xie, Y. & Al-Aly, Z. (2022). Long-term neurologic outcomes of COVID-19. *Nature Medicine*, 28, 2406–2415.

20. Huang, S., Zhou, Z., Yang, D., Zhao, W., Zeng, M., Xie, X., .... Liu, J. (2022). Persistent white matter changes in recovered COVID-19 patients at the 1-year follow-up. *Brain*, 145(5), 1830–1838.

depression, and sleep disturbances<sup>21</sup>. These symptoms can have a significant impact on the functioning, wellbeing and quality of life of people with Long COVID, who may require multidisciplinary support from healthcare and other sectors to support their recovery<sup>22</sup>.

### Learning Activity (10 mins)

Along with the potential causes listed above, a better understanding of risk and protective factors for Long COVID is beginning to emerge in the international

21. Samper-Pardo, M., Oliván-Blázquez, B., Magallón-Botaya, R., Bartolome-Moreno, C., & Leon-Herrera, S. (2023). The emotional well-being of Long COVID patients in relation to their symptoms, social support and stigmatization in social and health services: a qualitative study. *BMC Psychiatry*, 23, 68.
22. Haneef, R., Fayad, M., Fouillet, A., Sommen, C., Bonaldi, C., Wyper, G.M.A. .... Gally, A. (2023) Direct impact of COVID-19 by estimating disability-adjusted life years at national level in France in 2020. *PLoS ONE* 18(1): e0280990.

literature. The strength and quality of evidence supporting these factors and our knowledge of them will likely change and develop in the coming years.

Answer the following questions to review current knowledge about risk and protective factors for Long COVID.




*An interactive H5P element has been excluded from this version of the text. You*

*can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#h5p-17>

23. Guzman-Esquivel, J., Mendoza-Hernandez, M. A., Guzman-Solorzano, H. P., Sarmiento-Hernandez, K. A., Rodriguez-Sanchez, I. P., Martinez-Fierro, M. L., Paz-Michel, B. A., Murillo-Zamora, E., Rojas-Larios, F., Lugo-Trampe, A., Plata-Florenzano, J. E., Delgado-Machuca, M., & Delgado-Enciso, I. (2023). Clinical Characteristics in the Acute Phase of COVID-19 That Predict Long COVID: Tachycardia, Myalgias, Severity, and Use of Antibiotics as Main Risk Factors, While Education and Blood Group B Are Protective. *Healthcare*, 11(2), 197.
24. Durstenfeld, M. S., Peluso, M. J., Peyser, N. D., Lin, F., Knight, S. J., Djibo, A., ... & Beatty, A. L. (2023). Factors Associated with Long Covid Symptoms in an Online Cohort Study. *Open Forum Infectious Diseases*, 10(2), ofad047.
25. Wong, M. C. S., Huang, J., Wong, Y. Y., Wong, G. L. H., Yip, T. C. F., Chan, R. N. Y., ... & Chan, F. K. L. (2023). Epidemiology, Symptomatology, and Risk Factors for Long COVID Symptoms: Population-Based, Multicenter Study. *JMIR Public Health and Surveillance*, 9(1), e42315.
26. Abu Hamdh, B., & Nazzal, Z. (2023). A prospective cohort study assessing the relationship between long-COVID symptom incidence in COVID-19 patients and COVID-19 vaccination. *Scientific Reports*, 13, 4896.
27. Hirahata, K., Nawa, N., & Fujiwara, T. (2022). Characteristics of Long COVID: Cases from the First to the Fifth Wave in Greater Tokyo, Japan. *Journal of Clinical Medicine*, 11(21), 6457.
28. Tam, C. C., Qiao, S., Garrett, C., Zhang, R., Aghaei, A., Aggarwal, A., & Li, X. (2022). Substance use, psychiatric symptoms, personal mastery, and social support among COVID-19 long haulers: A compensatory model. *medRxiv*, 2022-11.

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29. Florencio, L. L., & Fernández-de-Las-Peñas, C. (2022). Long COVID: Systemic inflammation and obesity as therapeutic targets. *The Lancet Respiratory Medicine*, 10(8), 726-727.
  30. Cazé, A. B. C., Cerqueira-Silva, T., Bomfim, A. P., de Souza, G. L., Andrade Azevedo, A. C., Aguiar Brasil, M. Q., ... & Boaventura, V. S. (2022). Prevalence and risk factors for long COVID after mild disease: a longitudinal study with a symptomatic control group. *medRxiv*, 2022-09.
  31. Khan, N., Mahmud, N., Patel, M., Sundararajan, R., & Reinisch, W. (2023). Incidence of Long COVID and impact of medications on the risk of developing Long COVID in a nationwide cohort of Inflammatory Bowel Disease patients, *Journal of Crohn's and Colitis*, 17 (Supp 1), i392–i393
  32. Heubner, L., Petrick, P.L., Güldner, A. et al. (2022). Extreme obesity is a strong predictor for in-hospital mortality and the prevalence of long-COVID in severe COVID-19 patients with acute respiratory distress syndrome. *Scientific Reports*, 12, 18418.
  33. Sudre, C. H., Murray, B., Varsavsky, T., Graham, M. S., Penfold, R. S., Bowyer, R. C., ... & Steves, C. J. (2021). Attributes and predictors of long COVID. *Nature medicine*, 27(4), 626-631.
  34. Crook, H., Raza, S., Nowell, J., Young, M., & Edison, P. (2021). Long COVID – Mechanisms, risk factors, and management. *British Medical Journal*, 374, n1648
  35. Paul, E., & Fancourt, D. (2022). Health behaviours the month prior to COVID-19 infection and the development of self-reported long COVID and specific long COVID symptoms: a longitudinal analysis of 1581 UK adults. *BMC Public Health*, 22, 1716.



## *What are the symptoms of Long COVID?*

One of the great challenges Long COVID poses is the diversity of its associated symptoms. The syndrome can impact any and all **body functions** and **body structures**, with over 200 distinctive symptoms identified by people with Long COVID across 56 countries<sup>36</sup>. Some people may experience only one or two symptoms, while others may experience a constellation of multiple symptoms. As indicated in the figure below, the pervasive effect of the SARS-Cov-2 virus is mediated by its ability to use ACE2 receptors as a means of entering multiple organs.

36. Davis, H. E., Assaf, G. S., McCorkell, L., Wei, H., Low, R. J., Re'em, Y., ... & Akrami, A. (2021). Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*, 38, 101019.

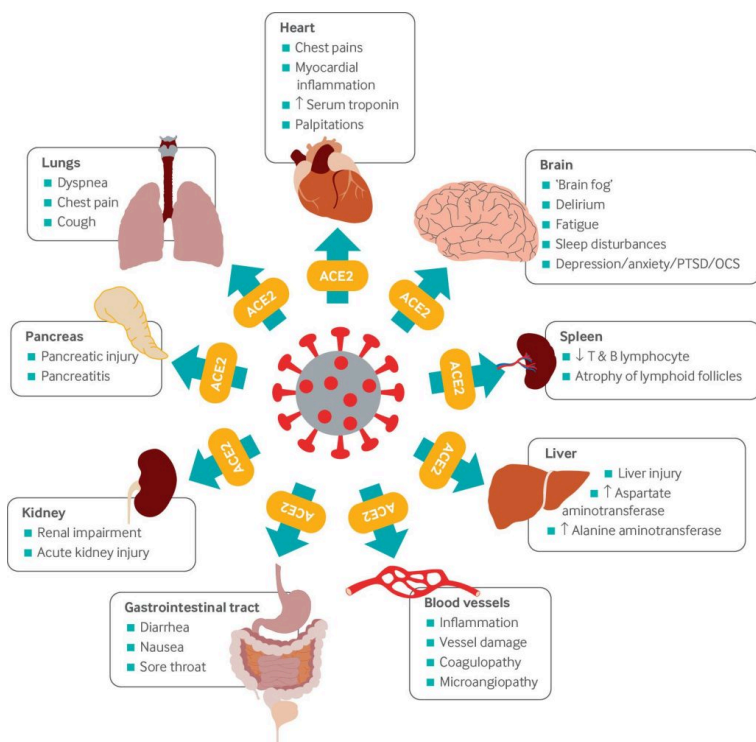


Figure by Crook et al. Licenced by BMJ Publishing Group (5517481246197).

## Learning Activity (15 mins)

Some of the more common symptoms of Long

COVID are listed below and were identified from a systematic review and meta-analysis of multiple studies<sup>37</sup>. Word-finding puzzles are a great way to remember new concepts and are much more fun than memorising a list!



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

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### **What does that mean?**<sup>38</sup>

- Ageusia – *Loss of taste*
- Anosmia – *Loss of smell*
- Apnoea – *Breathing disruptions*
- Dyspnoea – *Breathlessness*
- Dysphonia – *Voice changes*
- Palpitations – *Forceful or irregular heartbeat*
- Polypnea – *Rapid breathing*

37. Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C., Sepulveda, R., Rebolledo, P. A., Cuapio, A., & Villapol, S. (2021). More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *Scientific reports*, 11(1), 16144.

38. Marcovitch, H (Ed). (2017). *Black's Medical Dictionary*, 43rd Edition. A&C Black.

- Sputum – *Secretions that you cough up*
- Tachycardia – *Abnormally high heart rate*
- Tinnitus – *Noise or ringing in your ears or head not explained by external sounds.*

The diversity of possible symptoms for Long COVID has led some researchers to try and identify specific **phenotypes** of symptoms that tend to occur together. Up to 33 characteristics have been identified within the overall Long COVID phenotype<sup>39 40</sup>. Another general Long COVID phenotype was also shown to differentiate between people effectively hospitalised with Long COVID symptoms from those managed in the community or with no history of COVID-19 infection<sup>41</sup>.

Several sub-phenotypes have also been proposed, describing between 3 and 33 distinctive symptom clusters. Some of these

39. Deer, R. R., Rock, M. A., Vasilevsky, N., Carmody, L., Rando, H., Anzalone, A. J., ... & Robinson, P. N. (2021). Characterizing long COVID: deep phenotype of a complex condition. *EBioMedicine*, 74, 103722.
40. Estiri, H., Strasser, Z. H., Brat, G. A., Semenov, Y. R., Patel, C. J., & Murphy, S. N. (2021). Evolving phenotypes of non-hospitalized patients that indicate long COVID. *BMC medicine*, 19, 1-10.
41. Mayor, N., Meza-Torres, B., Okusi, C., Delanerolle, G., Chapman, M., Wang, W., ... & de Lusignan, S. (2022). Developing a Long COVID Phenotype for Postacute COVID-19 in a National Primary Care Sentinel Cohort: Observational Retrospective Database Analysis. *JMIR Public Health and Surveillance*, 8(8), e36989.

sub-phenotypes are also characterised by the number of symptoms they include, with those involving more symptoms generally considered more severe<sup>42 43 44</sup>. There is considerable diversity in identified sub-phenotypes, with some overlap between the various clusters of symptoms between the studies. This reflects the complexity of Long COVID and the emerging nature of the research in this field. However, identifying Long COVID phenotypes remains an important goal to ensure consistency across studies, facilitate comparisons between different populations, identify high-risk patients and develop targeted treatment and management strategies for COVID-19.

- 42. Kenny, G., McCann, K., O'Brien, C., Savinelli, S., Tinago, W., Yousif, O., ... & Mallon, P. W. (2022, April). Identification of distinct long COVID clinical phenotypes through cluster analysis of self-reported symptoms. In *Open Forum Infectious Diseases* (Vol. 9, No. 4, p. ofac060). US: Oxford University Press.
- 43. Zhang, H., Zang, C., Xu, Z., Zhang, Y., Xu, J., Bian, J., ... & Kaushal, R. (2023). Data-driven identification of post-acute SARS-CoV-2 infection subphenotypes. *Nature Medicine*, 29(1), 226-235.
- 44. Frontera, J. A., Thorpe, L. E., Simon, N. M., de Havenon, A., Yaghi, S., Sabadia, S. B., ... & Galetta, S. L. (2022). Post-acute sequelae of COVID-19 symptom phenotypes and therapeutic strategies: A prospective, observational study. *Plos one*, 17(9), e0275274.

## Learning Activity (15 mins)

Read a persona of your choice from this textbook (see [Persona section](#)). List the symptoms the person identifies and their associated body structure or system. You may also draw an outline of the human body and map the symptoms visually. Reflect on the following questions:

How many symptoms do they experience, and what body structures or systems are affected?

Have some of the symptoms changed or resolved over time?

How do the symptoms they have experienced following COVID-19 infection relate to any pre-existing health problems?

Choose an activity of daily living identified as meaningful or important to the person, and imagine them performing this task. Which symptom/s are likely to impact their participation? How might these symptoms pose a barrier to them completing this activity?

## What does it feel like to recover from COVID-19?

This section, “What does it feel like to recovery from COVID-19”, is adapted from [“Beyond the case numbers: Social determinants and contextual factors in patient narratives of recovery from COVID-19”](#), used under [CC BY 4.0](#). The cross section of people in this research study are not representative of everyone with Long COVID. As noted in the original article, some participation made a quick and full recovery, others recovered over time, and some were still experiencing significant ongoing symptoms. Participants simply had a history of COVID-19 infection and were asked to tell their story (including symptoms and the impact on their daily life) since they received their positive test result. There could never be a ‘one size fits all’ approach to COVID-19 recovery or Long COVID because the syndrome impacts patients’ lives in many ways. A person with Long COVID is the only one who can identify if and/or when they have recovered sufficiently to be ‘back to their normal’.

The narratives of COVID-19 recovery in this section come from an ongoing Australian study, which seeks to understand how patients describe their lived experience of COVID recovery. Five key themes have been identified in their stories: 1) Getting back to my normal, 2) Trajectories of recovery, 3) The importance of work, 4) Fears and uncertainties and 5) Stigma and discrimination.

## *Getting back to my normal*

### **Activity & Participation**

For most people, the destination for COVID-19 recovery was getting 'back to normal'. This was conceptualised as their 'normal' rather than an externally defined standard, and therefore recovery looked different for each

participant. Despite this individual variation, people recovering from COVID-19 could evaluate and describe their personal recovery to a high degree of specificity. Some people described their ongoing recovery from COVID-19 in reference to their symptoms, particularly those who experienced complete recovery; This emphasis on symptoms was also reflected in narratives of post-acute investigations, where test results or professional opinions often conflicted with the lived experience of recovery. The inability of healthcare representatives to explain why they didn't feel better when test results indicated full recovery was particularly frustrating and disconcerting for many people.

However, in most narratives, being 'back to normal' involved more than resolving symptoms. Most described how their participation in daily life changed as their recovery progressed and described how COVID-19 had an impact on all areas of their daily life, including personal and domestic activities, hobbies, exercise, and social or community activities. People who were recovering (rather than recovered) from COVID-19 described dissatisfaction with their current ability to take part in life roles and daily activities. Some had initiated a process of adaptation in response to their residual symptoms and functional issues to maintain some connection with these activities, albeit using a modified format or process. Therefore, recovery entailed adjusting to a new sense of 'my normal' rather than returning to their baseline.



Uncertainty about what sort of ‘normal’ could be expected post-COVID-19 was also a prevalent theme. ‘Normal’ for people with pre-existing conditions already included persistent symptoms and functional impairments, which made it difficult to determine what experiences were directly attributable to COVID-19. Many also wondered if their current health resulted from COVID-19 infection, normal ageing, or the pervasive societal changes everyone has experienced due to the pandemic. ‘My normal’ is perceived within the context of the ‘new normal’ to which everyone has needed to adjust. During the earlier phases of the pandemic, public health measures such as restrictions and lockdowns were a compounding factor that delayed or impeded recovery for some people with COVID-19; The impact of these measures on usual levels of physical activity was also described in several narratives as particularly detrimental to cardiovascular, respiratory, and musculoskeletal recovery.

**Only people recovering from COVID-19 can define what ‘their normal’ looks like, and they are best placed to evaluate their progress towards it.**

- “I think I’m pretty well getting back to normal now” (*Female, Aged 50+*)
- “I’m like 90% back to not having the impacts of it” (*Male, Aged 30-49*)

**Symptoms provide a benchmark for progress towards recovery.**

- “[The health department] cleared me on the 18th, and that was purely according to my symptoms.” (*Female, Aged 30-49*).

- “I got an email from the [health department] just telling me I’m well enough to go back to work. It was 10, 11 [days] or something. So, I rang them, and I said, no, no, no, you obviously haven’t communicated between you all. I’m still really not well enough” (Female, Aged 50+).
- “The resounding response from everybody is we don’t know ... It’s okay; your lungs are okay. Uh, yes, we can see that [you’re] not right. (Female, Aged 30-49)

**COVID-19 recovery is also about what the symptoms mean to your ability to participate in daily life.**

- “I was feeling quite reckless, getting from our bedroom, which was on the first floor, down to the kitchen and back again. So I struggled with that for a couple of weeks, but now, all sort of well and recovered” (Female, Aged 50+)
- “I’m back, walking, playing golf, doing all the things that I do” (Male, Aged 50+).
- “I can’t carry out my daily activities as well, pre-COVID diagnosis. So, they’re the main things that I’m dealing with at the moment” (Female, Aged 30-49).
- “So, it’s stuff that I’m adapting to, to make sure that I am still managing it well, but it is just something that I’ve had to adjust to.” (Female, Aged 18-29)

**What even is normal anymore?**

- “You will be talking and then, but again, I’m 62 ... (is) this a sign of something else? What was that word? Or what was that?” (*Female, Aged 50+*).
- “I think the biggest trauma’s been to be honest in my opinion, the lockdowns and the emotional stress of that side of it” (*Male, Aged 50+*).
- “I don’t know whether I’m just going to put it down to the fact that I couldn’t get over the lack of fitness in my legs after four weeks of doing not much around home, like you couldn’t even go for a walk around the block” (*Male, Aged 50+*).

## *Trajectories of Recovery from COVID-19*

The participants in the study described three distinct trajectories of recovery: 1) complete recovery, 2) gradual improvement and 3) cyclic/relapsing. Around a third of the narratives described complete recovery, with symptoms resolving during their acute illness. While the focus of this textbook is on Long COVID, it remains important to understand all aspects of recovery from the COVID-19 infection as a potential route to prevention and early intervention. The complete recovery trajectory was predominantly described by younger participants, some of whom recovered before their diagnosis.

However, most people recounted new or persisting symptoms that improved gradually and had progressively less impact on daily life. The speed of improvement varied between participants and between specific symptoms. This slow but steady trajectory also impacted pre-existing conditions for

some participants, which were exacerbated by COVID-19 and took many months to return to baseline. It is important to note that the World Health Organisation case description for Long COVID <sup>45</sup> explicitly excludes symptoms that can be attributed to another diagnosis, meaning these patients would not necessarily be identified as having the syndrome.

The third trajectory described cycles of alternating relapse and improvement within an overall course of gradual improvement. Some people experienced a period of feeling better or 'normal' before symptoms returned or new problems emerged. Relapses also occurred on a background of gradual improvement, with periods of improvement or plateaus generally becoming longer over time. However, experiences of this trajectory differed from sustained gradual improvement, as their journey felt 'bumpier'.

**Younger people most often reported complete recovery during the acute phase of their COVID-19 infection.**

- “I got a phone call on the Wednesday saying that I tested positive, and I was actually completely fine at the time ... it was like a bit of a cold for one or two days and then just left”  
*(Female, Aged 18-29).*

**Recovery from COVID-19 is most often a process of slow but steady improvement.**

45. World Health Organisation. (2021). A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021. World Health Organisation.

- “It was a real slow process of feeling better. I went out for some exercise probably [a] week after that, and I could walk maybe 200 metres, and then that was it” (*Female, Aged 30-49*)
- “So the palpitations are less prominent now, but I still get palpitations most days. And that’s the main feature of my day” (*Female, Aged 30-49*).
- “After COVID for the first two or three months, my sugar was everywhere. But my sugar has improved a lot, we had got that back on track” (*Male, Aged 50+*).

**Relapses, plateaus and improvements can all occur within a gradually improving recovery.**

- “Five weeks, six weeks ... I felt like nothing ever happened, did resume as normal activity as I could during lockdown, but then afterwards it kinda came back, and that’s when I thought, Oh God, have I got it again, because (it felt like) what I’ve had in May” (*Male, Aged 30-49*).
- “So it’s sort of like a two spike sort of attack. It gets really hard, then you get better and then it comes back and hits you a second time” (*Male, Aged 50+*).

## Learning Activity (30 mins)

Return to the persona that you chose for the previous learning activity. In this activity, you will be drawing a patient journey map that describes their experience of

Long COVID to date. A patient journey map is a diagram of a patient's experience with a healthcare provider or healthcare system. It shows the patient's interactions, experiences, and emotions throughout their healthcare journey, from the initial point of contact through treatment and follow-up care. The map outlines key 'touch points' in the patient's journey – these are experiences or contacts with the provider or system which provide an opportunity to improve the patient's experience. Mapping these 'touch points' enables healthcare practitioners to identify areas for improvement in providing patient-centred care.

The following brief video provides an example of patient journey mapping through planning, receiving and recovering from surgery. It shows how every aspect of the person's care is identified for point in their assessment and treatment.



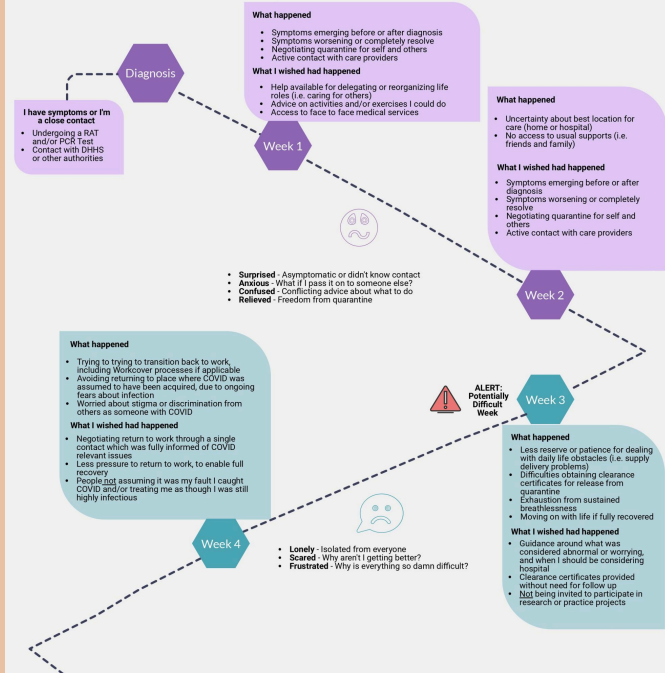


*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#oembed-2>*

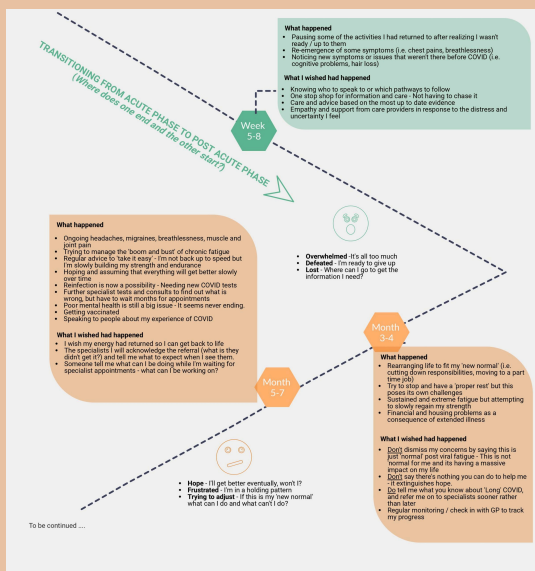
However, not all patient journey maps are focused exclusively on healthcare services or systems. In late 2021, the following patient journey map was co-produced with six people experiencing Long COVID. The map's purpose was to illustrate how their lived experience changed over time, although there are references to some of the contacts they had with healthcare providers. Review this map, and in particular, consider how visual features are used to convey the contents and changes over time.

# Life After COVID

## Common Features of the Recovery Journey







*"Patient Journey for People Developing Long COVID" by [Danielle Hitch](#) is licensed under [CC BY 4.0](#).*

Draw a patient journey map for your chosen persona.

You may choose to focus on their healthcare interactions, their lived experience or both. You may choose any format, visuals or aspects of the persona you wish. While this activity can be completed individually, you may find it more helpful to work within a pair or team to ensure multiple perspectives are incorporated into your map.

## *The importance of work*

Many people think of paid employment when considering work; however, there are other productive activities that may be impacted by COVID-19 recovery (including education, voluntary duties and childcare). While the people in this study mostly spoke about paid employment, it is likely their experiences are also relevant to other forms of work. Returning to work was a key sign that things were returning to 'my normal' for many people recovering from COVID-19. This was particularly true for healthcare workers, who described the additional stress caused by returning to where they had acquired the virus. Return to work processes were also often experienced as onerous and prevented people from moving beyond their experiences of COVID. Assessment and documentation requirements were an even greater burden for people experiencing brain fog and other functional issues.

Similar to their recovery trajectories, people recounted various return-to-work pathways. Some returned to their previous roles, although the initial weeks were often marked by significant fatigue. Others required a graded return to work with progressively longer hours, while some moved to new positions better suited to their 'new normal'. Often these new positions involved fewer hours or less demanding duties to take their ongoing symptoms into account, which had a negative impact on their income and potential career progression. The provision of specialist vocational rehabilitation support for these consumers would prevent a considerable loss of productivity to the broader community but is not always available under local jurisdictions and healthcare systems. Implementation of reasonable accommodations in the workplace may also need legislative support, such as recognition of Long COVID as a disability within disability discrimination legislation.

### **Healthcare workers recovering from COVID-19 face distinctive challenges regarding their work.**

- “it’s very triggering to come back into that environment and continually face that over and over again” (*Female, Aged 30-49*).
- “You are dealing with a few different agencies, you are sort of dealing with your own line management, you are dealing with the [health department] and then in my case I was dealing with [organisation name] as well... and anyone else who wants to know if you are alright. So, you end up dealing with a lot, talking about COVID a lot.” (*Male, Aged 30-49*).
- “I’m working as a **PPE** spotter. That’s all I can do [...] for the foreseeable future ... because I’m still not ready to look after a patient. I don’t have the brain concentration. I don’t have the energy.” (*Female, Aged 30-49*).

### **Access to and requirements for vocational rehabilitation and return to work support vary significantly.**

- “So the response to COVID by [my] employer has been kind of okay. My husband’s has been appalling. They’re insane and they don’t communicate and their leadership has really been shown up. It’s extremely poor. Disaster. Complete morons, I work at [employer] and they’ve been the total opposite. Absolutely excellent. So the stress associated with the ridiculous behavior of the [husband’s employer]

- has not helped as well.” (*Female, Aged 30-49*).
- “I was, when I did come back to work I was offered all the support services, like the counseling people that go through work, I can’t remember what their name was but I was offered that as a choice. You know, I could even do that if I still even want to two now, which probably wouldn’t be a bad idea to sort of download it all to someone else other than me”. (*Female, Aged 18-29*).
  - “The support to access [organisation] to get paid **OHS** leave, those support mechanisms weren’t really there. And even returning to work was quite challenging and I think underappreciated, it’s not just kind of being unwell. There is this sort of stigma, this sort of stigma that does sit with it.” (*Male, Aged 30-49*).
  - “But in terms of at a systems level, they’ve got really no clue from an HR or workplace rehab. I really like our workplace rehab coordinator, but I was offering and sending her information.” (*Female, Aged 30-49*).

## *Fears and uncertainties*

A complex range of psycho-social factors influences and interact with the lived experience of people recovering from COVID-19. Many people described their fears about Long COVID, some of which related to new symptoms developed following their infection. Study participants also acknowledged

they might have become hyper-vigilant about symptoms. Still, they had few ways of checking whether their concerns were reasonable given how little is known about Long COVID. The abrupt disruption experienced by many following acute illness was also traumatic, but few had access to mental health support. An additional contributor to the stress experienced by healthcare workers was a sense of shame for 'letting themselves' get infected, given their professional responsibilities to practice good infection control. Other people also discussed the guilt they experienced when they were 'patient zero' in their social group, especially if they felt they had passed on the virus to a vulnerable friend or relative. The overall lack of certainty or detailed knowledge about the syndrome was, therefore, very disruptive to their mental health and overall well-being.

**Post COVID-19 symptoms can provoke anxiety or be overwhelming.**

- “My biggest fear is like choking to death or drowning, something where my oxygen, you know, where I can't breathe. So, during this sort of process my anxiety level has increased, because the symptoms are mimicking, what I fear most” (*Male, Aged 30-49*).
- “Now anything that happens like that, we look at it sideways and wonder if it's COVID”. (*Female, Aged 50+*)
- “Yeah, it is a massive challenge, and if I had a direction in which to go, rather than just going for test after test, which is what we've been doing ... you don't know when it's going to end”. (*Female,*

*Aged 30-49).*

**Many people recovering from COVID-19 struggle to obtain support for its emotional impact.**

- “All these emotions just started coming out, and I didn’t even know I was holding onto it, and I just started crying ‘cause I just said, I just don’t feel myself... he said, “we probably don’t need to go to the point of an antidepressant at the moment, but he said, you know, obviously it’s something on the radar”. *(Female, Aged 30-49).*
- “There was a lot of talk around lapses in PPE and errors in putting it on and taking it off ... it felt like to all of us were kind of shamed and a bit of blame for that. It was our fault for getting infected”. *(Female, 30-49)*

## *Stigma and discrimination*

The final theme describes the stigma and discrimination many people recovering from COVID-19 have experienced due to their condition or the broader conditions of the pandemic. The following three vignettes illustrate how this experience has continued long after the initial turmoil and confusion of the pandemic had passed.





*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#h5p-21>

## Conclusion

Two perspectives on the question “What is Long COVID?” have been presented in this chapter – the current knowledge of healthcare researchers and practitioners and the lived experience expertise of patients. Clearly, this syndrome is far more than a collection of commonly co-occurring symptoms. The COVID-19 pandemic has been as much a social phenomenon as a global healthcare emergency, and the knowledge required to engage with its pervasive impact (including Long COVID) originates from multiple disciplines and ways and understanding<sup>46</sup>. Long COVID, in particular, highlights the complex and constant interplay between the multitude of biopsychosocial factors that influence health and well-being. No wonder researchers, healthcare practitioners and patients alike feel overwhelmed.

46. Leach, M. (2020). Pandemics are social phenomena, demanding breadth of expertise. WONKHE. Available at <https://wonkhe.com/blogs/pandemics-are-social-phenomena-demanding-breadth-of-expertise/>

As highlighted in this chapter, recovering from COVID-19 and Long COVID means different things to different people, and a 'one size fits all' approach cannot be applied. Our knowledge of Long COVID is evolving at lightning speed, with multiple new challenges and opportunities always emerging. However, it doesn't always feel like this for people with Long COVID as much of the progress to date has remained within the research and development realm. Ultimately, Long COVID reminds us of the inherent unpredictability of life and spotlights the limitations of our knowledge. It forces us to confront the fact that sometimes we have to live with uncertainty and discomfort – for the foreseeable future, we will be 'flying the plane while building it'.<sup>47</sup> This chapter has, therefore, just scratched the surface of what there is to know and understand about Long COVID ... but we all have to start somewhere.

## For More Information

The following links will provide you with additional general information about Long COVID from creditable sources. These listings are not exhaustive, and you are

47. Hitch, D. (2023). Long COVID: Why isn't anyone listening? Available at <https://insightplus.mja.com.au/2023/8/long-covid-why-isnt-anyone-listening/>



encouraged to seek out locally relevant information for your community.

### **World Health Organisation**

#### Children and Adolescents

[A clinical case definition for post COVID-19 condition in children and adolescents](#)

#### [Webinar on Post COVID-19 Condition in Children](#)

#### Adults

#### [A clinical case definition of post COVID-19 condition](#)

[Coronavirus Disease \(COVID-19\): Post COVID-19 Condition Questions and Answers](#)



*One or more interactive elements has been excluded from this version of the text. You can view them online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=24#oembed-3>

### **Australian College of General Practice**

[Post-COVID-19 syndrome/condition or long COVID: Persistent illness after acute SARS CoV-2 infection](#)

### **Australian Institute of Health and Welfare**

[Long COVID in Australia – A review of the literature](#)

Please consider providing us with some feedback via the following satisfaction survey to help us ensure this textbook meets the needs of all readers:

[Brief Feedback Survey – What is Long COVID](#)

[Chapter](#). If you have any additional feedback, suggestions or recommendations for improvement

to this chapter, please email the editors at

**covidtextbook@deakin.edu.au.**

## References

## PART II

# ACTIVITIES AND PARTICIPATION

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

Activities and Participation are two of the categories of the International Classification of Function (ICF). Activity is “the execution of a task or action by an individual”.<sup>1</sup> Participation is “involvement in a life situation”<sup>2</sup>.

The nine combined ICF chapters for activity and participation are listed below, and each contains a list of components (see [here](#) for more information).

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care

1. Centres for Disease Control and Prevention. (2010). The ICF: An overview. Available at [www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](http://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)
2. Centres for Disease Control and Prevention. (2010). The ICF: An overview. Available at [www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](http://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)

- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life

## 2.

### Pacing to Enable Participation

*Olivia Richards and Danielle Hitch*

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

You may find some material in multiple chapters (such as an introduction to common symptoms of Long COVID) because we anticipate some readers will only access certain chapters. Please feel free to skip any material you are already familiar with.

The goal of this chapter is to present evidence-based strategies that help individuals with Long COVID engage in daily activities while managing fatigue and/or pain. Pacing, which involves balancing activity with rest, is a key strategy for avoiding overexertion and effectively controlling symptoms. By grasping the principles of pacing and how to implement them, informed and shared decision-making can assist people with Long COVID in enhancing their health, wellbeing, and quality of life. This chapter is designed to empower both clinicians and people with Long COVID to better manage energy levels, decrease the frequency and severity of symptom flare-ups, and

progressively improve or sustain their ability to **participate** in everyday life.

## Learning Objectives

After reading this chapter and completing the learning activities you will be able to:

- Understand the concept of pacing and its importance in managing fatigue in Long COVID
- Identify key strategies for effective pacing.
- Recognise the signs of over exertion.
- Plan and apply pacing techniques in daily activities to manage energy levels.
- Utilise tools and resources to support pacing strategies.

# Introduction

The World Health Organisation (WHO) describes Long COVID as “the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation”<sup>1</sup>. More recently, the National Academies

of Sciences, Engineering, and Medicine (NASEM) have released an updated definition, describing Long COVID as “an infection-associated chronic condition (IACC), specifies a minimum duration of 3 months, and expressly incorporates common symptoms and diagnosable conditions characteristic of Long COVID”<sup>2</sup>. This definition provides symptom examples, recognises intermittent symptoms, and emphasises equity in care. It also recognises that exacerbation of existing symptoms can be a manifestation of Long COVID, in contrast to the WHO description which explicitly excludes symptoms which can be attributable to a pre-existing condition.

The impact of Long COVID on participation in daily life can be profound. People may struggle with basic tasks, experience

Go to [What is Long COVID?](#) for more detail.

1. World Health Organization. Post COVID-19 Condition (Long COVID) [Internet]. [www.who.int](https://www.who.int). 2022 [cited 2024 Jul 13]. Available from: <https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition>
2. The National Academies of Sciences, Engineering, and Medicine. A Long COVID Definition [Internet]. National Academies Press eBooks. 2024 [cited 2024 Jul 13]. Available from: <https://nap.nationalacademies.org/read/27768/chapter/4>

difficulties in maintaining relationships, and face emotional challenges such as anxiety and depression provoked by their ongoing issues. Creating individually tailored strategies to manage symptoms and enhance overall well-being is crucial to enabling people with Long COVID to fully participate in own lives and communities<sup>3</sup>. This chapter will provide readers with practical tips, tools, and resources to support both clinicians and people with Long COVID to successfully apply pacing techniques in everyday life.

## Signs and Symptoms

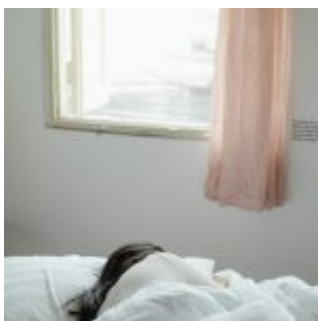
The symptoms of Long COVID differ significantly from one person to another, making accurate identification and management difficult<sup>4</sup>. Fatigue is one of the most common

3. O' Mahony L, Buwalda T, Blair M, Forde B, Lunjani N, Ambikan A, et al. Impact of Long COVID on health and quality of life. HRB Open Research. 2022 Apr 22;5:31]. Rehabilitation for people with Long COVID can include a diverse range of interventions, including education about getting high quality rest and sleep and skill building for managing energy levels. All interventions should be founded on individualised approaches to activity and energy management, which establish activity patterns that align with current energy levels and implement mutually agreed self-management strategies that quickly respond to flare-ups or relapse. This can involve identifying potential triggers, temporarily reducing activity levels, monitoring symptoms over time, and avoiding a return to normal activity levels until symptoms have subsided [footnote]Long COVID Physio [Internet]. Long COVID Physio. 2014 [cited 2024 Jul 11]. Available from: <https://longcovid.physio/rehabilitation>

4. National Health Service. Long-term Effects of COVID-19 (long



features of Long COVID and is categorised into two types: physical fatigue, which results from repeated muscle use, and cognitive fatigue, often referred to as "brain fog"<sup>5</sup>.



*Fatigue is a major barrier to taking part in daily life.*

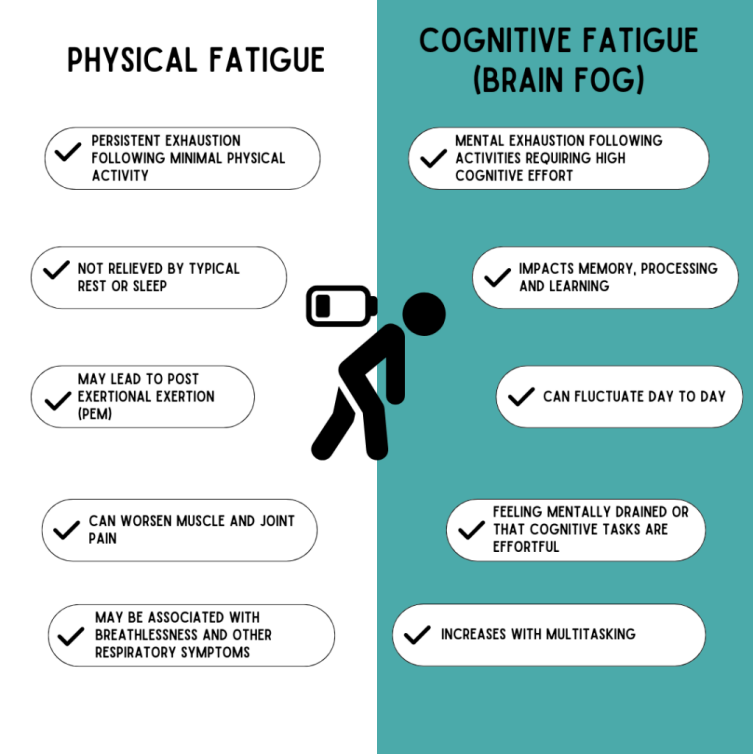
*Photo by [Ketut Subiyanto](#) from [Pexels](#).*

*"Something most people take for granted is being able to get out of bed and shower or wash daily. This is now a major task for my friend, and requires a lot of pacing and planning. Her bed is her best friend at present. Life is passing by on a daily basis, she can see life outside her window*

*but cannot be part of it. Cognitive function has been taken from her and what she could do she cannot even think about now"*<sup>6</sup>.

COVID) [Internet]. nhs.uk. 2023 [cited 2024 Jul 15]. Available from: <https://www.nhs.uk/conditions/covid-19/long-term-effects-of-covid-19-long-covid/>

5. Australian Institute of Health and Welfare. Long COVID in Australia – a Review of the literature, Summary [Internet]. Australian Institute of Health and Welfare. 2022 [cited 2024 Jul 12]. Available from: <https://www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary>
6. Long Covid. Long Covid Scotland [Internet]. Long Covid



“Features of fatigue in Long COVID” by [Danielle Hitch](#) is licensed under [CC BY 4.0](#).

Scotland. 2014 [cited 2024 Jul 14]. Available from:  
<https://www.longcovid.scot/blog/tag/Lived+Experience>

References:<sup>7 8 9 10</sup>

Many people with Long COVID also experience sleep disturbances, which are related to a range of symptoms, pulmonary function and their functional capacity<sup>11</sup>. These problems may include problems with falling asleep, staying asleep, or waking up too early. Poor sleep quality exacerbates fatigue and must be considered as part of any strategy to assist people with Long COVID manage their feelings of fatigue<sup>12</sup>.

7. Kunasegaran K, Ismail AMH, Ramasamy S, Gnanou JV, Caszo BA, Chen PL. Understanding Mental Fatigue and its Detection: A Comparative Analysis of Assessments and Tools. PeerJ [Internet]. 2023 [cited 2024 Jul 13];11:e15744. Available from: <https://pubmed.ncbi.nlm.nih.gov/37637168/>
8. Centers for Disease Control. Signs and Symptoms of Long COVID [Internet]. COVID-19. 2024 [cited 2024 Jul 14]. Available from: <https://www.cdc.gov/covid/long-term-effects/long-covid-signs-symptoms.html>
9. Gross M, Lansang NM, Gopaul U, Ogawa EF, Heyn PC, Santos FH, et al. What Do I Need to Know About Long-Covid-related Fatigue, Brain Fog, and Mental Health Changes? Archives of Physical Medicine and Rehabilitation [Internet]. 2023 Mar [cited 2024 Jul 14];106(6). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10028338/>
10. National Health Service. Long-term Effects of COVID-19 (long COVID) [Internet]. nhs.uk. 2023 [cited 2024 Jul 15]. Available from: <https://www.nhs.uk/conditions/covid-19/long-term-effects-of-covid-19-long-covid/>
11. Horvath G, Percze AR, Nagy A, Polivka L, Zsuzsanna K, Varga JT, Müller V. Sleep quality in long COVID-19 patients: relation to symptoms, pulmonary function and functional capacity. Sleep & Breathing disorders. 2023
12. Gross M, Lansang NM, Gopaul U, Ogawa EF, Heyn PC, Santos FH, et al. What Do I Need to Know About Long-Covid-related

Before moving on, watch the following video summary of how fatigue and PESE presents in people with Long COVID to consolidate your learning.



*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=1534#oembed-1>*

Fatigue, Brain Fog, and Mental Health Changes? Archives of Physical Medicine and Rehabilitation [Internet]. 2023 Mar [cited 2024 Jul 14];106(6). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10028338/>

## What is pacing?

Pacing is a self-management strategy designed to prevent Post-Exertional Symptom Exacerbation (PESE). Pacing involves performing less activity than your maximum energy level allows, breaking activities into shorter segments, and incorporating frequent rest periods. It provides a tailored approach to managing Long COVID symptoms, recognising that each person's journey to recovery is unique<sup>15</sup>.

The primary goal of pacing is to manage energy levels, prevent overexertion, and minimise the risk of energy crashes. By prioritising tasks and

**Also known as Post Exacerbation Malaise (PEM), PESE is an exacerbation of symptoms following physical, cognitive, or emotional exertion that would have been previously manageable. This exacerbation can occur immediately or with a delayed onset, typically ranging from hours to days after the exertion.**<sup>13</sup>

<sup>14</sup>.

13. Faghy MA, Dalton C, Duncan R, Arena R, Ashton REM. Using cardiorespiratory fitness assessment to identify pathophysiology in long COVID - Best practice approaches. *Progress in cardiovascular diseases*. 2024;83:55-61.
14. Long COVID Physio. Post-Exertional Symptom Exacerbation [Internet]. Long COVID Physio. 2024 [cited 2024 Jul 15]. Available from: <https://longcovid.physio/post-exertional-symptom-exacerbation>
15. Long COVID Physio. Pacing [Internet]. Long COVID Physio. 2023 [cited 2024 Jul 15]. Available from: <https://longcovid.physio/pacing>

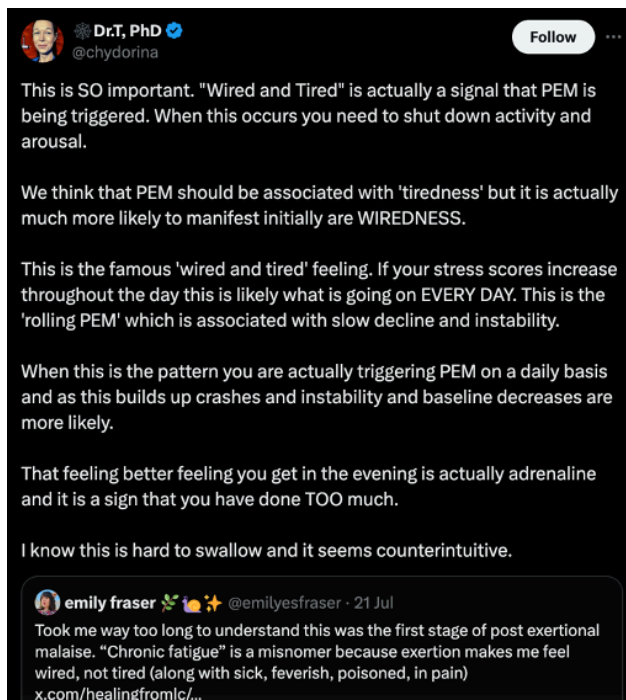
incorporating regular breaks, people with Long COVID can more effectively conserve energy throughout the day, resulting in a balanced energy expenditure.

Pacing is a highly individualised process, with each person's journey varying based on their unique circumstances, abilities, and goals. Some individuals may focus on maintaining their current energy levels rather than increasing their activity, while others might experience gradual improvements that enable them to slowly increase participation. Additionally, some individuals may go through periods of remission, allowing them to significantly enhance their activity levels. Therefore, effective pacing strategies must be customised to meet each person's specific needs, abilities, and goals to achieve the best possible outcomes.

## Recognising and Screening for Post-Exertional Symptom Exacerbation (PESE)

Recognising and screening for Post-Exertional Symptom Exacerbation (PESE) is crucial for effective Long COVID management using pacing and improving the quality of life for those affected. Early PESE identification and management prevent symptoms worsening and overall deterioration in health and wellbeing, that people with Long COVID receive appropriate care and support. Early screening can address these issues by enabling timely interventions and management strategies tailored to individual needs. Traditional diagnostic criteria often fail to fully capture the extent or severity of PESE symptoms. Currently, few tests are available specifically for assessing brain fog, and existing diagnostic tools often lack the sensitivity needed to accurately detect this complex symptom. Consequently, patients

frequently experience delays in diagnosis and healthcare professionals often lack confidence in recognising and managing PESE.



*Tweet by @chydorina via X (formerly known as Twitter)*

This tweet describes a way of recognising PESE which draws on the lived experience of people with Long COVID. It describes the value of recognising the "wired and tired" feeling as a signal that PESE

may be triggered. This description challenges the assumption that PESE is only about feelings of fatigue, and reinforces the idea that everyone's experience of Long COVID is different. Dr. T also explains that increasing stress levels increase throughout the day can occur if PESE is triggered frequently, referring to this as "rolling PEM." This pattern can cause gradual decline, instability in health and wellbeing, lowered baseline and an increased risk of flare ups. When screening for the presence of PESE or monitoring it over time, remember to look for more than just physical and cognitive fatigue.

## *Methods for Recognising and Screening for PESE*

There are two primary approaches for recognising and screening for PESE:

### **Patient's Lived Experience:**

Self-Monitoring: People with Long COVID should be encouraged to monitor their symptoms and energy levels regularly and in a standardised way. This can be achieved by keeping detailed diaries, activity logs, or utilising wearable technology to track exertion and symptom patterns.

Patient Reports: People with Long COVID are experts in their own experience of the syndrome. Their subjective reports provide valuable insights into the impact of PESE on their health and wellbeing and must be incorporated into shared decision making with healthcare professionals.

### **Screening Tools:**

[DePaul Post-Exertional Malaise Questionnaire \(DSQ-PEM\):](#)



This tool was designed specifically to detect PESE and is available in original, brief and paediatric versions.

**Fatigue Assessment Scale (FAS):** This 10-item scale evaluates general symptoms of chronic fatigue, however it is not specifically designed to detect PESE.

**Fatigue Severity Scale (FSS):** This tool quantifies the impact of fatigue on daily life, including its relationship to motivation, physical activity, work, family, and social life.

Both approaches for recognising PESE should be employed to gain a comprehensive understanding of this symptoms. Remember: Low scores on the screening tools does not negate the presence or severity of PESE <sup>16</sup>.

*When you find the right balance between activity and rest, you can:*

- Participate in more activities that are personally meaningful and important
- Break the cycle of 'boom and bust' (explained in this chapter)
- Have better control over your energy levels

16. Skilbeck L, Spanton C, Paton M. Patients' lived experience and reflections on long COVID: an interpretive phenomenological analysis within an integrated adult primary care psychology NHS service. Journal of Patient-Reported Outcomes [Internet]. 2023 Mar 20 [cited 2024 Aug 4];7(1). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10027259/>

throughout the day

The hardest thing about pacing is **changing existing (and often long practiced) behaviors to create new habits and routines, a process that is neither simple nor linear. Behavior change is challenging because it is cognitively demanding** - you are asking people to break old habits while simultaneously developing new and unfamiliar actions. These changes often take much longer than expected. For example, a change as simple as drinking an extra cup of water daily takes about two months to become a consistent habit. When helping people with Long COVID make behavior changes, setbacks may be mistakenly perceived as laziness or stubbornness. However, seeing setbacks as opportunities for mutual reflection and problem-solving will increase the likelihood of success. Understanding and accepting that setbacks are part of the behavior change process can help both clinicians and people with Long COVID achieve significant their goals<sup>17</sup>.

17. Accelerate Learning Community. Why is Behavior Change So Hard? [Internet]. Izzo E, Call M, editors. accelerate.uofuhealth.utah.edu. 2022 [cited 2024 Jul 14]. Available from: <https://accelerate.uofuhealth.utah.edu/resilience/why-is-behavior-change-so-hard#:~:text=Behavior%20change%20is%20complicated%20and>

Reflect on a time your own life when you tried to build a new habit. Did you succeed? How long did it take? What helped you succeed or stood in the way of success? Who did you turn to for help and support?

It is important and helpful to recognise that establishing new behaviours and habits requires **repeating a chosen behavior in the same context until it becomes automatic and effortless by integrating it into the daily routine**. When a behaviour becomes part of a routine, it requires less conscious effort and decision-making, decreasing its cognitive demand and increasing the likelihood of it being sustained over time. All of which enables people with Long COVID to maintain or gradually increase their participation in daily life<sup>18</sup>.

Before moving on, watch the following video to consolidate your general knowledge about pacing as a strategy for people with Long COVID.



*One or more interactive elements has been excluded from this version of the text. You can*

18. Gardner B, Lally P, Wardle J. Making health habitual: the psychology of “habit-formation” and general practice. *British Journal of General Practice* [Internet]. 2012 Dec [cited 2024 Jul 17];62(605):664–6. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3505409/>

view them online here: <https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=1534#oembed-2>

## Theories Underlying Pacing

There are many theories and analogies to explain the rationale for pacing and how it works. People with Long COVID may already be familiar with one or more of them, and clinicians should aim to use theories that resonate with each individual. There is no single way to understand Long COVID, so choose a way of explaining your reasons for recommending pacing that enhances understanding without leading to information overload. Some of these theories include:

### Boom/Bust Theory

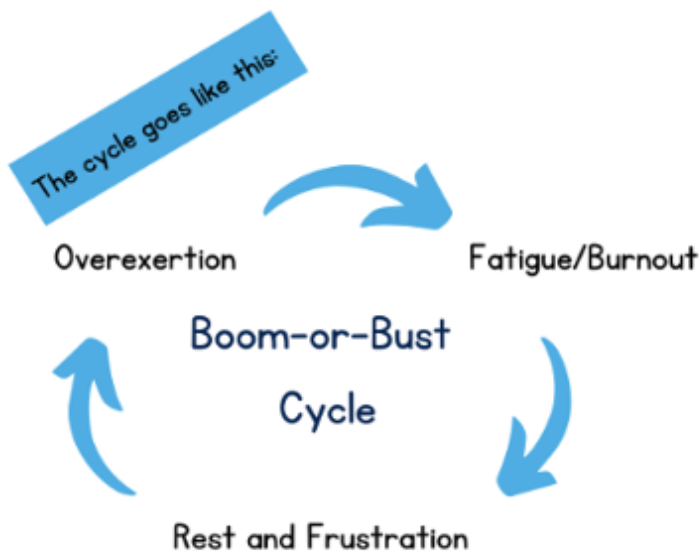
The Boom-and-Bust theory describes a cycle in which individuals with chronic health conditions go through periods of high energy use, followed by fatigue or worsening symptoms. The "boom" phase involves increased activity or exertion, which is then followed by the "bust" phase, characterized by a significant drop in energy and functioning that can last for days<sup>19</sup>. On days when energy levels are higher,

19. Agency for Clinical Innovation. Chronic pain and brain injury – Boom and bust [Internet]. aci.health.nsw.gov.au. 2021 [cited

people often feel motivated to accomplish tasks and may try to make up for lost time<sup>20</sup>. This can lead to overexertion and ignoring the body's signals, resulting in a subsequent "crash." Continuously pushing beyond one's limits can cause more severe fatigue and longer recovery times, ultimately leading to a reduction in overall activity levels over time<sup>21</sup>.

2024 Jul 14]. Available from: <https://aci.health.nsw.gov.au/chronic-pain/brain-injury/fatigue/boom-and-bust>

20. Neef M. The Neurodivergent Spoon Drawer: Spoon Theory for Autism and ADHD [Internet]. Insights of a Neurodivergent Clinician. 2024 [cited 2024 Jul 16]. Available from: <https://neurodivergentinsights.com/blog/the-neurodivergent-spoon-drawer-spoon-theory-for-adhders-and-autists>
21. Austin Health. Pacing yourself [Internet]. Articulate.com. 2024 [cited 2024 Jul 15]. Available from: [https://rise.articulate.com/share/TD6hr7OIRLI5SBrexuGcGcYv0TbaKyn1#/lessons/vrHIKU9Y-O20hZ2a4NmITf\\_exllqNghi](https://rise.articulate.com/share/TD6hr7OIRLI5SBrexuGcGcYv0TbaKyn1#/lessons/vrHIKU9Y-O20hZ2a4NmITf_exllqNghi)



*"Boom or Bust Cycle" by Olivia Richards is licensed under [CC BY 4.0](https://creativecommons.org/licenses/by/4.0/).*

## Spoon Theory

Spoon theory is a metaphor used to describe the limited energy available to individuals with chronic illnesses. In this metaphor, each "spoon" represents a unit of energy required for daily tasks, and people with chronic conditions must carefully allocate their spoons to manage their activities throughout the day<sup>22</sup>. Unlike those without such conditions,

22. Cleveland Clinic. What Is the Spoon Theory Metaphor for Chronic Illness? [Internet]. Cleveland Clinic. 2021 [cited 2024 Jul

who may have what feels like an unlimited supply of energy, individuals with chronic illnesses start each day with a finite number of spoons. This theory helps explain the concept of pacing by highlighting the importance of conserving energy to avoid exhaustion. Everyone has a different number of spoons, and by using strategies like rest and self-care, individuals can potentially increase their supply of spoons over time<sup>23</sup>.

16]. Available from: <https://health.clevelandclinic.org/spoon-theory-chronic-illness>

23. Natale G, Pai M. "Spend your spoons wisely": Conceptualizations of time, energy and aging invisibly with Crohn's Disease. *Innovation in Aging* [Internet]. 2021 Dec 1 [cited 2024 Jul 14];5(Supplement\_1):600–1. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8968325/>



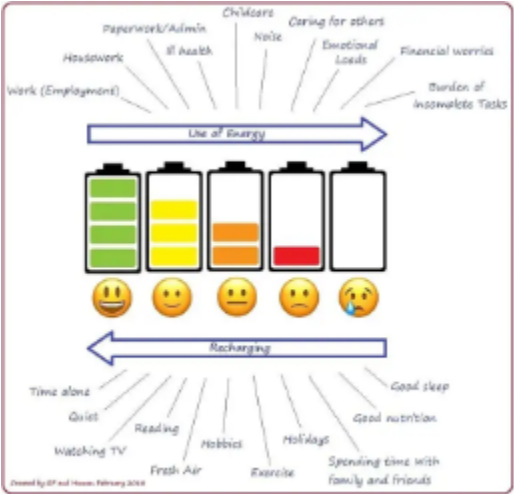
"Spoon Theory in daily life" by Olivia Richards is licensed under [CC BY 4.0](https://creativecommons.org/licenses/by/4.0/).

## Battery Theory

The battery life metaphor is a helpful way to understand energy management for individuals with chronic conditions. Imagine your energy as a mobile phone battery. If you completely drain the battery, you'll have to wait for it to recharge before you can use the phone again. Similarly, if you exhaust your energy



reserves, you'll need significant rest to recover. By using only part of the battery and recharging it regularly, your phone stays ready for use. This approach highlights the importance of balancing activity with rest. By managing energy through planned periods of activity and rest, individuals can maintain a more consistent energy level, allowing them to participate in desired activities more effectively. This metaphor illustrates the principles of pacing, demonstrating how careful energy management can improve daily functioning<sup>24</sup>.



*"Battery Theory" by Olivia Richards s licensed under [CC BY 4.0](https://creativecommons.org/licenses/by/4.0/).*

24. FND Hope. Balancing Energy and Pacing [Internet]. [cited 2024 Jul 15]. Available from: <https://fndhope.org/wp-content/uploads/2015/11/Balancing-Energy-and-Pacing-new-FND-copy.pdf>

For the remainder of this chapter, we will be using the persona of Jennifer for learning activities. Please take the time to review [Jennifer's story](#) before continuing.

### 3 P's Principle

The 3 P's Principle for Pacing is a practical strategy designed for use in daily life, to help manage energy levels and avoid overexertion<sup>25</sup>. This strategy encompasses three key components: Pace, Plan, and Prioritise.

#### PACE

To pace, you need to think how you approach tasks, aiming to perform them more slowly or divide them into smaller segments with breaks. It ensures you have enough energy to complete activities without worsening fatigue. In contrast,

25. National Health Service. How to Conserve Your Energy [Internet]. 2023 Aug [cited 2024 Jul 16]. Available from: <https://www.qvh.nhs.uk/wp-content/uploads/2020/08/How-to- conserve-your-energy-0130.pdf>

pushing yourself to exhaustion means you'll need a longer recovery period<sup>26</sup>.

The basis of successful pacing is a comprehensive understanding of the various demands each activity places on a person. These may include:

Physical Demands	e.g. moving, standing, reaching
Mental Demands	e.g. concentrating, remembering, understanding information, speaking, reading, writing
Sensory Demands	e.g. noise, light, temperature.
Emotional Demands	e.g. excitement, stress, upset, fear, sadness
Environmental Demands	e.g. objects and places at home, work, school and in the community
Task Demands	e.g. time demands, opportunities to adjust the way the activity is completed

*General Strategies for Effective Pacing*

- Break activities into smaller tasks and distribute them throughout the day.
- Adjust different aspects of an activity to lower

26. National Health Service. How to Conserve Your Energy [Internet]. 2023 Aug [cited 2024 Jul 16]. Available from: <https://www.qvh.nhs.uk/wp-content/uploads/2020/08/How-to- conserve-your-energy-0130.pdf>

energy demands.

- Incorporate rest periods into your activities to recharge.
- Pause and rest between activities whenever possible.
- Sit and rest whenever you can.
- Reschedule activities to less busy times of day.
- Seek help from others where possible.
- Postpone non-urgent tasks until you have more urgently.

### *Using Pacing*

One of Jennifer's goals was to keep on top of her laundry more effectively. Her current approach is to complete the laundry all in one go in a 'big push'. She reports she needs to rest for 20 minutes after folding the clothes, and reported feeling achy and more fatigued the next day.

With the support of her clinician, she broke down this activity into more manageable steps:

1. **Gathering clothes:** Jennifer collects dirty clothes from her basket, for 5 minutes, then takes a 10-minute break.

2. **Loading the washer:** After resting, she loads the washer slowly, taking a small break halfway through. Then breaks again after the washing is loaded, and the washing cycle has begun.
3. **Moving clothes:** When the washing cycle ends, she transfers to clothes to the washing basket, taking a longer 15-minute break to recover, before hanging them on the clothing rack.
4. **Folding clothes:** Finally, she folds the laundry taking short breaks after each small pile.

## PLAN

As shown in the previous example, planning activities ahead of time provides the groundwork for pacing. By examine the activities the person typically engages in over the entire day or week, a plan can be created to distribute these activities more evenly. This plan will reflect each person's individual circumstances, taking into account personal interests, environment, and current level of functioning. A daily or weekly plan can include scheduled times for rest and recovery and arrange activities for times of day when the person feels more energetic <sup>27</sup>. Activities that already cause the person an increase in fatigue, breathlessness or pain are particularly good

27. National Health Service. How to Conserve Your Energy [Internet]. 2023 Aug [cited 2024 Jul 16]. Available from: <https://www.qvh.nhs.uk/wp-content/uploads/2020/08/How-to- conserve-your-energy-0130.pdf>

targets for breaking into smaller parts for completion over a longer period of time. An established plan also helps to reduce stress and cognitive load, and help to establish your current baseline for activity<sup>28</sup>.

Pacing plans should be reviewed and re-evaluated every 1-3 months to ensure it remains aligned with the person's current condition and needs. This regular assessment helps to track progress, adjust to any changes in symptoms or energy levels, and incorporate new strategies as necessary. It also ensures that the plan continues to support the goals as they evolve.

### *General Strategies for Effective Prioritisation*

Consider the following questions to determine which tasks are essential and non-essential.

- What are my must-do activities for today?
- What activities would I like to engage in today?
- Which tasks can be postponed for another day?
- Are there any tasks I can ask someone else to complete for me?

Other strategies

- Be gentle with yourself and avoid the pressure to accomplish everything.

28. Long COVID Physio. Pacing [Internet]. Long COVID Physio. 2023 [cited 2024 Jul 15]. Available from: <https://longcovid.physio/pacing>

- Strive for a balance between necessary and desired activities.
- If possible, delegate or eliminate tasks.
- Seek out activities that boost your energy levels.
- Instead of lifting items, try to push or slide them whenever you can.
- Remember to bend at your knees rather than your waist when picking things up.

### *Using Planning*

With the support of her clinician, Jennifer drew up a weekly activity plan which included the following strategies for her laundry.

- **Complete laundry during high energy window:** Jennifer will complete her washing before lunchtime, when her energy levels are at their highest.
- **Efficient setup:** Jennifer has positioned washing baskets next to her washing machine and her shower to minimise walking to and from the bedroom with the laundry basket. She has also placed her clothing rack near the washing machine to reduce unnecessary movement.
- **Rest Period:** Jennifer has scheduled brief rest periods after each small step, and a larger one

after starting the machine, and finishing her washing.

## Prioritise

Prioritising helps individuals decide which activities must be completed at a specific time, and which can be delayed or deemed unnecessary. While some daily tasks are essential, others may not be as critical which provides opportunities for the establishment of new habits <sup>29</sup>. This process involves identifying the personal importance of activities, which reflects individual priorities and circumstances - what might be important for one person is not important to another. This approach allows for a more balanced daily routine, reducing stress related to incomplete tasks while ensuring the person can complete as many of their responsibilities as possible <sup>30</sup>.

29. National Health Service. How to Conserve Your Energy [Internet]. 2023 Aug [cited 2024 Jul 16]. Available from: <https://www.qvh.nhs.uk/wp-content/uploads/2020/08/How-to- conserve-your-energy-0130.pdf>
30. Royal College of Occupational Therapists. Lift Up Your Everyday - Managing energy [Internet]. Royal College of Occupational Therapists. 2024. Available from: <https://www.rcot.co.uk/lift-up-your-everyday/lift-up-your-everyday-by-managing-energy>



### *General Strategies for Effective Planning*

- Prepare in advance when possible.
- Establish consistent routines.
- Distribute activities over time.
- Organise the placing of necessary items so they are easily accessible.
- Seek out tools or equipment that can help minimise effort.
- Monitor and record your energy expenditure.

The following TikTok demonstrates an effective approach to prioritising weekly activity. It highlights the value of identifying essential tasks and then scheduling other activities around these priorities.

[@positively\\_fatigued](#)

PACING is 🗝️ Anyone else do this on their Monday mornings? It used to be the Sunday evening Outlook calendar review to see what the next work week held, but now its making sure I don't have a "big" activity (going to the Doctor, a social event, golf, etc) more than 3 days a week, and ensuring that I plan lots of rest. As well as weekly pacing, I am now in the habit of daily pacing. If I do ANYTHING that invovles movement (putting a wash on, making breakfast, driving, walking to the shop), I make sure I sit/lie down and rest before doing more movement. It's unbelievable that this is my life now, but I trust that if I keep looking after myself

and pacing well, I will get back to my favourite activities again soon. [#longcovid](#) [#longcovidrecovery](#)  
[#longcovidawareness](#) [#longcovidsymptoms](#)  
[#longhaulers](#) [#longcovidwellness](#) [#chronicfatigue](#)  
[#pacing](#) [#morningroutine](#) [#mondaymotivation](#)  
[🎵 Bittersweet Symphony - Vitamin String Quartet](#)

### *Using Prioritisation*

With the support of her clinician, Jennifer identified which activities were most important to her and some modifications to others that she felt comfortable with.

- **Complete essential washing only:** Jennifer will wash only the clothes she needs for the next 2-3 days, ensuring each load is light.
- **Delegate Task:** Jennifer will ask her partner for assistance to retrieve the wet and therefore heavier clothes out of the washing machine, reducing physical strain.
- **Folding clothes:** Jennifer will choose which items need to be folded and which could be placed directly in her cupboard.
- **Balance domestic and leisure activities:** After completing the essential laundry tasks, Jennifer will read her book, a low-energy activity she enjoys, to balance her day.

### Activity (5 minutes)

Having read the examples above, answer the following questions:

1. What else could Jennifer do to **pace** her laundry activities?
2. What else could Jennifer do to further **plan** her laundry activities?
3. What else could Jennifer do to **prioritise** aspects of her laundry activities?

## Using the 3P's strategy on other daily activities

The 3P's strategy can be used for any and all activities in daily life. See below for a range of strategies and approaches you can use for specific activities when working with a person with Long COVID.



*An interactive H5P element has been excluded from this version of the text. You can view it online [here](#):*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=1534#h5p-50>

## Grading or modifying activities

Balancing activity and rest is essential for managing fatigue and reaching daily functional goals. The initial focus should be on achieving a balance where tasks can be completed without overwhelming fatigue. Once this balance is maintained and symptoms remain stable—typically for about a month—it suggests that the current pacing strategies are working effectively. When the person is ready to increase their activity levels, clinicians should work closely with them to determine the right timing and method for gradual progression. The goal is to safely and steadily enhance daily activity while closely monitoring fatigue levels and overall function. Generally speaking, this process starts with a specific time or task limit and gradually builds from there<sup>31</sup>.

Ongoing symptom monitoring is vital for tracking progress and identifying any flare-ups or relapses. Progress varies among individuals but often people make quicker advances with activities which are aligned with their interests or needs.

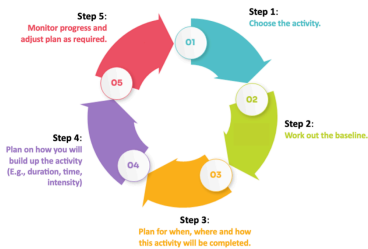
31. FND Hope. Balance - FND Hope International [Internet]. FND Hope International. 2020 [cited 2024 Jul 16]. Available from: <https://fndhope.org/living-fnd/healthy-living/balance-2/#1440649454683-b771bca0-51a2>

For example, a person with Long COVID might focus on participation in activities like self-care while also improving their engagement with leisure pursuits such as knitting. However, they may also choose to maintain their current level of activity in tasks like meal preparation if this is less of a priority for them<sup>32</sup>. Starting the process of improvement with just one or two key areas at a time provides a greater sense of control and decreases the risk of flare-ups causing pain and discomfort. Gradually increasing activity, with careful monitoring, can eventually lead to higher overall activity levels and improved function but the maintenance of current levels of participation may also be a meaningful goal in the context of a person's overall health and wellbeing.

Ongoing monitoring of symptoms is essential to track improvements and detect any flare-ups or relapses. Gradual increases in activity, monitored carefully, can eventually lead to greater overall activity levels and improved function. It's important to recognise that progress can vary among individuals. Some individuals may advance in certain areas based on their interests or needs. For instance, they might make progress in essential activities like self-care, while also enhancing leisure activities such as knitting. However, they might choose to maintain their current level of activity for tasks like meal preparation, particularly if they find cooking less enjoyable. It's crucial to tailor the approach to each individual's specific needs and goals, focusing on what is most relevant and motivating for them<sup>33</sup>.

32. Austin Health. Building Up [Internet]. Articulate.com. 2024 [cited 2024 Jul 15]. Available from: [https://rise.articulate.com/share/TD6hr7OIRLI5SBrexuCgGcYv0TbaKyn1#/?lessons/HfgWLGbV32ABPzoEWn\\_sim3mZcL5gt8m](https://rise.articulate.com/share/TD6hr7OIRLI5SBrexuCgGcYv0TbaKyn1#/?lessons/HfgWLGbV32ABPzoEWn_sim3mZcL5gt8m)
33. Austin Health. Building Up [Internet]. Articulate.com. 2024 [cited 2024 Jul 15]. Available from: <https://rise.articulate.com/>

As mentioned before, changing habits and activity patterns can be incredibly challenging. Starting with one or two key areas at a time can offer a sense of control and may help in managing pain and discomfort. Building up by taking small steps can and does add up over time. As shown below, pacing is a continuous cycle of change, re-evaluation and adjustment.



*"The Pacing Cycle" by Olivia Richards is licensed under [CC BY 4.0](#).*

## A pacing plan in action

As stated above, a clinician worked with Jennifer to implement pacing strategies in her daily life. The following process illustrates how the steps in the cycle played a part in increasing her participation.

### 1. Choose the activity/activities

Jennifer and her clinician discussed the daily activities she wanted to do, and chose to focus on doing the laundry. Selecting a single activity simplified the introduction of pacing strategies and minimised the demands of changing habits.

### 2. Baseline

share/TD6hr7OIRLI5SBrexuGgGcYv0TbaKyn1#/lessons/  
HfgWLGbV32ABPzoEWn\_sim3mZcL5gt8m

It is essential to establish the persons baseline level of participation before introducing pacing. A baseline is the amount of activity that can be done on a good day or bad day, without leading to a flare up or over-exertion<sup>34</sup>. Identify the activities that tend to exacerbate the person's symptoms and assess how long they can do them without increasing either fatigue or pain.

**It is crucial not to exceed the persons baseline level of activity to avoid exacerbating fatigue.** Determining a baseline can be difficult because symptoms may fluctuate from day to day. To overcome this issue, you may need to monitor activity and participation for the person on both good and bad days over a span of 3 to 7 days, and then calculate the average to determine your baseline level. Once the persons baseline has been assessed, reduce the activity by 20% as your starting point. This ensures they will be able to adhere to the pacing strategy consistently, regardless of whether they are having a good or bad day<sup>35</sup>.

*For example; Jennifer and the clinician estimate that she can manage around 20 minutes of laundry work before becoming fatigued. The starting point for her pacing strategy is therefore 15 minutes of activity.*

Watch the following video for a summary of the process for setting a baseline level of activity.

34. FND Hope. Balance - FND Hope International [Internet]. FND Hope International. 2020 [cited 2024 Jul 16]. Available from: <https://fndhope.org/living-fnd/healthy-living/balance-2/#1440649454683-b771bca0-51a2>
35. Botha M. Activity Pacing | Newcastle Integrated Physiotherapy [Internet]. Newcastle Integrated Physiotherapy. 2021 [cited 2024 Jul 24]. Available from: <https://newcastleintegratedphysiotherapy.com.au/activity-pacing/>



One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=1534#oembed-3>

### 3. Plan for when, where and how activities are completed.

Clearly define the when, where, and how of your activity. The more specific these definitions are, the more helpful they will be to the person in their plan. Utilise the 3 P's strategy—pace, plan, and prioritise—to effectively integrate these elements into your overall plan<sup>36</sup>.

Rest breaks are important and should be scheduled into the pacing plan to lessen the risk of over-exertion and flare-up. Think about what activities are completed during this time, and the amount of rest they offer. They may offer physical rest, cognitive rest or both depending on the person's needs.

*For example; Jennifer and her clinician discuss a range of options for rest such as changing positions, going for a short walk and medication. Jennifer likes to physically rest by completing some brief stretching exercises, and she prefers to mentally rest by listening to music. These activities are scheduled into her day, either singly or together.*

Other strategies that might can help people with Long COVID with planning include:

36. Botha M. Activity Pacing | Newcastle Integrated Physiotherapy [Internet]. Newcastle Integrated Physiotherapy. 2021 [cited 2024 Jul 24]. Available from: <https://newcastleintegratedphysiotherapy.com.au/activity-pacing/>



- Setting a reminder on a phone or in a planner for when activities will occur,
- Inviting a friend or family member to join in
- Creating visual reminders (like sticky notes) in the place where the activity occurs
- Consideration of the order of activities during the day (i.e. which activities naturally flow on from each other?)
- Using AI platforms to automate the planning of activities. These can be programmed to take current activities and other parameters into account.
- Have the plan in multiple formats, such as in a diary, pinned to the fridge and as reminders in a phone.

Jennifer and her clinician come up with the following plan for her laundry tasks. Note the specific detail included in the plan, which makes it easier to judge whether it has been achieved or not. It may seem that this approach is 'micro managing' her day, but a higher level of guidance is needed initially when forming new habits and behaviours.

When?	Every 4th morning at 10am, after breakfast
Where?	Laundry at home
How?	<p><i>Total time require for a wash cycle = 1 hour, 28 minutes</i></p> <p>Place washing in washing machine (no more than 10 items of clothing) - [5 minutes]  <b>REST [5minutes]</b>  Place washing powder in washing machine, and start 50-minute wash [4 minutes]  <b>REST [2 minutes]</b>  COMPLETE OTHER TASK [48 minutes]  Get assistance with carrying clothes from machine [4 minutes]  <b>REST [5 minutes]</b>  Sit down to hang out washing on drying rack, without using pegs [10 minutes]  <b>REST [5 minutes]</b></p>
Support Strategies	<ul style="list-style-type: none"> <li>• Reminder in phone</li> <li>• Ask partner to remind her on 'washing days'</li> <li>• Note in calendar on kitchen wall</li> </ul>

#### 4. Plan how to grade or increase the activity.

Once the person with Long COVID feels comfortable with the first stage of their pacing program, plans can be made to gradually increase participation over time. Increases in activity must be undertaken slowly and with close monitoring of symptoms and overall comfort. As a guide, activity can be

increased by 10% per week <sup>37</sup>, but should be paused or even decreased if any signs of PESE or other health issues emerge.

Grading of an activity may be achieved by changing factors such as;

- Time taken or allowed to completed the task
- Distance travelled during activity
- Number of repetitions of movements or tasks
- Addition or subtraction of tasks as part of the activity
- Level of help or support received from others
- Frequency of activity performance

The 3P's (Pace, Plan, and Prioritise) also provide avenues for grading the activity. Although these increments might seem small, they can significantly impact overall energy expenditure and help prevent overexertion and flare-ups. The process of gradually increasing your activity is slow but rewarding. By following a structured approach, you allow your body to adjust and build endurance safely, which can lead to more sustainable improvements in your activity levels over time.

*For example; The first 2 weeks of Jennifer's pacing plan have been successful and she feel ready to try and increase her participation in laundry tasks. She wants to decrease the overall time she spends doing this activity, so based on the 10% guideline her rest periods are reduced from 5 minutes to 4 minutes and 30 seconds.*

## **5. Monitoring progress**

There are many ways for people with Long COVID to keep

37. Getting back to what you want to do - young painHEALTH [Internet]. young painHEALTH. 2023 [cited 2024 Aug 2]. Available from: <https://youngpainhealth.com.au/pain-management/getting-back-to-what-you-want-to-do/#:~:text=You%20can%20plan%20to%20increase>

track of the progress they make with pacing. Some may like to keep an activity log or booklet, some may choose to map their time visually while download data from their smart watch. Continuous and regular review and adjustment to the pacing plan, in line with the persons individual needs and goals, underpins momentum during recovery and also quickly identifies flare-ups or other problems<sup>38</sup>.

*For example; Jennifer chose to track the duration and intensive of her laundry tasks in a journal, where she also noted her fatigue (as a score out of 10 after completion). Over a two month period, her fatigue while doing this tasks reduced, but did not disappear completely. However, she was able to complete her laundry tasks in a reasonable timeframe and removed it from the next version of her plan to focus on other activities.*

38. Getting back to what you want to do - young painHEALTH [Internet]. young painHEALTH. 2023 [cited 2024 Aug 2]. Available from: <https://youngpainhealth.com.au/pain-management/getting-back-to-what-you-want-to-do/#:~:text=You%20can%20plan%20to%20increase>

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 1	√ 5/10				√ 5/10		
Week 2		Too tired	√ 7/10				√ 6/10
Week 3				√ 5/10			
Week 4	Too tired	Too tired	√ 5/10				√ 4/10
Week 5				√ 4/10			
Week 6	√ 4/10				√ 3/10		
Week 7		√ 3/10				Too tired	√ 4/10
Week 8			√ 2/10				√ 3/10

### Activity (20 minutes)

Choose another activity that Jennifer has identified as part of her goals. Work through the following steps to build a pacing plan for this activity. Information in her [persona](#) will provide you with some background regarding her baseline level of activity, but feel free to use some creative licence when completing these tasks.

1. Choose the activity
2. Establish a baseline
3. Plan how, when and where the activity will

be completed

4. Plan on how you will grade or modify the activity
5. Plan how you will monitor progress

Pacing plans may vary between the many different daily activities people with Long COVID undertake. Given the various factors that influence daily activities, plans may be slightly different for each of them. This can introduce a lot of complexity into a pacing plan, and therefore careful consideration must be given to how much (or little) you are working on at any one time. It may be helpful to think of the plan as a 'pipeline' where pacing is applied to a selection of activities at any one time. They enter the pipeline as they become a priority, and leave it when the person with Long COVID is comfortable with their performance and participation. The following information gives examples of abbreviated pacing plans for several other activities identified as important to Jennifer.

Gardening	<ul style="list-style-type: none"><li>• <b>Choose the Activity:</b> Start with an activity you enjoy or need to do more of, like weeding, which is manageable and enjoyable. Begin with something easy, such as light weeding or tending to plants.</li><li>• <b>Baseline:</b> Determine how long you can garden before experiencing increased pain or fatigue. For example, if you can manage 5-10 minutes of weeding followed by rest, use this as your baseline.</li><li>• <b>Plan for When, Where, and How:</b> When: every 3rd morning at 9 am, after breakfast. Where: In your backyard garden. How: Weeding (5 minutes), REST (5 minutes), Continue weeding (5 minutes), REST (5 minutes), Alternate tasks (e.g., planting, watering) for 15 minutes, REST (10 minutes)</li><li>• <b>Plan on How You Will Build Up the Activity:</b> Gradually increase your gardening time by about 1 minute each week. For instance, if you start with 5 minutes of weeding, aim to extend it to 6 minutes next week. Use a timer to keep track.</li><li>• <b>Monitoring Progress:</b> Track your progress with a gardening log or chart. Review and adjust your plan based on how well you manage the increased time and any symptoms you experience.</li></ul>
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Meal Preparation	<ul style="list-style-type: none"> <li>• <b>Choose the Activity:</b> Select meal preparation tasks that are essential or enjoyable, starting with simple tasks like chopping vegetables or preparing easy meals.</li> <li>• <b>Baseline:</b> Identify how long you can stand and prepare meals without discomfort. For example, if you can stand for 10 minutes before needing to rest, this is your baseline.</li> <li>• <b>Plan for When, Where, and How:</b> When: Prepare meals daily at 6pm. Where: In your kitchen. How: Stand and chop vegetables (5 minutes), REST (5 minutes), Continue meal prep (5 minutes), REST (5 minutes), Cook (10 minutes), REST (10 minutes).</li> <li>• <b>Plan on How You Will Build Up the Activity:</b> Increase your standing time by 1 minute each week. If you start with 10 minutes of standing while cooking, aim for 11 minutes the following week.</li> <li>• <b>Monitoring Progress:</b> Use a meal preparation log to monitor your standing times and adjust as needed. Keep track of how your symptoms respond to the increased activity.</li> </ul>
Shopping	<ul style="list-style-type: none"> <li>• <b>Choose the Activity:</b> Choose shopping activities that are manageable, like a small grocery trip or picking up a few items. Start with easier tasks.</li> <li>• <b>Baseline:</b> Establish how long you can shop without experiencing excessive fatigue or pain. For example, if you can handle 30 minutes of shopping comfortably, use this as your baseline.</li> <li>• <b>Plan for When, Where, and How:</b> When: Shop every Saturday at 10am Where: At your local supermarket. How: Shop (15 minutes), REST (5 minutes in a café or seating area), Continue shopping (15 minutes), REST (5 minutes), Complete shopping and checkout.</li> <li>• <b>Plan on How You Will Build Up the Activity:</b> Gradually increase your shopping duration or the number of items you buy by about 10% each week. If you start with a 30-minute trip, aim for 33 minutes the following week.</li> <li>• <b>Monitoring Progress:</b> Keep a shopping log to track the duration and any issues encountered. Adjust your plan based on your comfort level and any symptoms experienced.</li> </ul>



Walking	<ul style="list-style-type: none"><li>• <b>Choose the Activity:</b> Begin with a walking routine that is enjoyable and manageable, such as a short walk around the neighbourhood.</li><li>• <b>Baseline:</b> Determine how long or far you can walk without discomfort. For example, if you can walk for 15 minutes comfortably, use this as your baseline.</li><li>• <b>Plan for When, Where, and How:</b> Schedule your walks for specific times each day or every other day. Decide on your route and ensure you have appropriate footwear. When: Walk every morning at 8am. Where: Around your neighbourhood or local park. How: walk (10 minutes), REST (5 minutes), Continue walking (10 minutes), REST (5 minutes)</li><li>• <b>Plan on How You Will Build Up the Activity:</b> Increase your walking time, distance, or step count by 10% each week. For example, if you walk for 15 minutes, aim to walk for 16.5 minutes the following week.</li><li>• <b>Monitoring Progress:</b> Track your walking sessions with a pedometer or walking log. Monitor how you feel and adjust your plan as needed.</li></ul>
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Study	<ul style="list-style-type: none"><li>• <b>Choose the Activity:</b> Select study tasks that you need to complete regularly like watching online lectures and writing discussion board posts. Start with manageable periods of time.</li><li>• <b>Baseline:</b> Identify how long you can work at your computer without fatigue. For instance, if you can type for 20 minutes before needing a break, this is your baseline.</li><li>• <b>Plan for When, Where, and How:</b> Plan your study sessions by setting specific times and choosing a comfortable workstation. Incorporate ergonomic adjustments and breaks. When: Work from 9 am to 5 pm with scheduled breaks. Where: At university or at home. How: Type or work (20 minutes), REST (5 minutes, stand up, stretch), Continue working (10 minutes), REST (5 minutes), Complete task (20 minutes), REST (40 minutes).</li><li>• <b>Plan on How You Will Build Up the Activity:</b> Increase your seminar viewing or computer time by 2 minutes each week. For example, if you start with 20 minutes, aim for 22 minutes the following week.</li><li>• <b>Monitoring Progress:</b> Use a study log to track your typing duration and any discomfort. Adjust your plan based on how well you manage the increased time and any symptoms experienced.</li></ul>
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Cleaning	<ul style="list-style-type: none"><li>• <b>Choose the Activity:</b> Begin with a manageable cleaning task, such as vacuuming one room or dusting surfaces.</li><li>• <b>Baseline:</b> Determine how long you can clean without experiencing increased pain. For example, if you can vacuum for 10 minutes comfortably, use this as your baseline.</li><li>• <b>Plan for When, Where, and How:</b> Schedule your cleaning tasks for specific days and decide on the areas to clean. Plan how you will perform the tasks to minimise strain. When: Clean every Tuesday and Friday at 3 pm. Where: Focus on specific rooms or areas of your home. How: vacuum one room (10 minutes), REST (5 minutes), Vacuum another room or continue with another task (10 minutes), REST (5 minutes), Complete other cleaning tasks as needed (20 minutes), REST (20 minutes).</li><li>• <b>Plan on How You Will Build Up the Activity:</b> Gradually increase your cleaning time or the number of areas cleaned by about 5 minutes each week. For example, if you start with 10 minutes, aim for 15 minutes the following week.</li><li>• <b>Monitoring Progress:</b> Keep a cleaning log to track the duration and areas cleaned. Adjust your plan based on your comfort level and any symptoms experienced.</li></ul>
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### Activity (5 minutes)

Reflect on how many of these plans you would implement with Jennifer at any one time. Which do you think she would prioritise as an immediate focus?

### *Practical tips for staying on track*

Working on activity and participation levels can be challenging, but careful planning and strong support networks will help to achieve goals. Here are a recap of proven strategies to help your patients remain on track<sup>39</sup>.

- Use a planner or calendar
  - Begin by scheduling essential tasks first, including enjoyable activities, exercise, and relaxation time. This ensures the activities that matter most are prioritised within the daily routine.
- Set a timer for activities
  - Use a timer to monitor the duration of activity engagement. This will enable the patient to stick to their planned duration, even when they feel particularly energetic.
- Track activity patterns

39. Getting back to what you want to do - young painHEALTH [Internet]. young painHEALTH. 2023 [cited 2024 Aug 2]. Available from: <https://youngpainhealth.com.au/pain-management/getting-back-to-what-you-want-to-do/#:~:text=You%20can%20plan%20to%20increase>

- Keep a record of activity levels to identify trends and patterns, which can form the basis of adjustments to the pacing plan.
- Communicate the pacing plan
  - Share activity goals with family and friends so they can offer encouragement as part of a wider support system.
- Establish a realistic progression rate
  - While 10% increases may work for some patients, others may find a 2%-5% increase more manageable and effective.
- Practice regularly
  - Consistency is the key. Build new habits by incorporating planned activities into the patients daily routine and build momentum.
- Encourage persistence
  - It is important for the pacing plan to be followed as consistently as possible, through good days and challenging days. Consider providing the patient with guidelines for temporary reductions in activity intensity or increases in rest breaks to accommodate their energy levels.
- Create a setback plan
  - It is important to acknowledge there will be barriers to the implementation of the

pacing plan. Prepare for setbacks by having alternative activities in mind. For instance, if the patient plans to do weeding in the garden, have an alternative indoor activity in case the weather is inclement.

## **Assessments for monitoring the progress of pacing plans**

Along with PESE, other aspects of participation in daily life may need to be assessed and monitored during the implementation of a pacing program. Understanding how everyday activities affect energy levels, health and well-being enables the development of more effective and tailored pacing strategies. A wide range of assessment could be selected depending on the priorities and interests of the person with Long COVID. However, the following assessments provide some general options to consider:

<i>Outcome</i>	<i>Assessments</i>
<b>Participation in Daily Life / Activities of Daily Living</b>	<p><b><a href="#">Activity Logs / Time Log Diaries:</a></b> Activity logs record daily activities (including duration and intensity) to monitor how they affect energy levels and symptoms. Time use diaries record more detailed information about what a person with Long COVID is doing throughout the day, along with where they are doing it and who they are doing it with.</p> <p><b><a href="#">Canadian Occupational Performance (COPM):</a></b> This tool is designed to capture self-perception of performance and satisfaction in everyday living over time. This assessment can only be completed by Occupational Therapists.</p> <p><b><a href="#">Occupational Balance Questionnaire:</a></b> This tool evaluates a person's sense of occupational balance in relation to their current situation and daily life. This assessment can only be completed by Occupational Therapists.</p>
<b>Functional and Exercise Capacity Tests</b>	<p><b><a href="#">Post-COVID-19 Functional Status Assessment (PCFS):</a></b> This tool was specifically designed for people recovering from a COVID-19 infection, and measures the functional impact of COVID-19 on daily activities.</p> <p><b><a href="#">Work and Social Adjustment Scale (WSAS):</a></b> This tool assesses the impact of mental health difficulties that can result from developing Long COVID on functioning in work, home management, social leisure, and personal relationships.</p> <p>For more information, go to <b><a href="#">Improving the participation gap: Physiotherapy for people with Long COVID.</a></b></p>
<b>Self Management</b>	<p><b><a href="#">Occupational Self-Assessment (OSA):</a></b> This tool captures people's perceptions of their own occupational competence and the importance of various occupations. This assessment can only be completed by Occupational Therapists.</p>
<b>Sleep</b>	<p><b><a href="#">Epworth Sleepiness Scale (ESS):</a></b> This tool evaluates daytime sleepiness to help identify potential sleep disorders contributing to fatigue.</p>

Quality of Life	<p><b>EuroQOL EQ-5D-5L:</b> This tool measures quality of life across five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.</p> <p><b>WHODAS 2.0:</b> This tool assesses health and disability in domains such as understanding and communicating, getting around, self-care, and participation in society.</p>
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# Conclusion

Pacing is a deliberate approach to balancing activity and rest, with the goal of gradually increasing activity levels while carefully managing fatigue. Effectively managing Long COVID requires a comprehensive understanding of Post-Exertional Symptom Exacerbation (PESE) and skills in the practical application of pacing strategies. Recognizing and responding to fatigue and PESE is the foundation for maintaining energy balance and preventing over-exertion and flare ups.

Healthcare professionals can more accurately tailor management plans to individual needs by conducting assessments based on both lived experience and formalised screening tools. These evaluations inform sustainable and effective pacing plans which incorporate baseline establishment, detailed planning of activities, and gradual increases in participation<sup>40</sup>. The examples and case studies included in this chapter demonstrate that even small, incremental improvements can lead to significant progress

40. Botha M. Activity Pacing | Newcastle Integrated Physiotherapy [Internet]. Newcastle Integrated Physiotherapy. 2021 [cited 2024 Jul 24]. Available from: <https://newcastleintegratedphysiotherapy.com.au/activity-pacing/>



over time <sup>41</sup>. Sharing practical tips such as using planners, timers, and support systems can further enhance the ability of people with Long COVID to manage symptoms and achieve their goals. Pacing is a key strategy in the management of Long COVID <sup>42</sup> and you now have all the knowledge you need to offer it as an option for your patients.

### *Chapter Key Points*

- Pacing is a deliberate approach to balancing activity and rest, with the goal of gradually increasing activity levels while carefully managing fatigue.
- Recognising Post-Exertional Symptom Exacerbation (PESE) is vital for maximising the health and wellbeing of people with Long COVID, with symptoms like feeling "wired and tired" indicating a need for better pacing.
- Healthcare professionals should consider both

41. Long COVID Physio. Pacing [Internet]. Long COVID Physio. 2023 [cited 2024 Jul 15]. Available from: <https://longcovid.physio/pacing>

42. Getting back to what you want to do - young painHEALTH [Internet]. young painHEALTH. 2023 [cited 2024 Aug 2]. Available from: <https://youngpainhealth.com.au/pain-management/getting-back-to-what-you-want-to-do/#:~:text=You%20can%20plan%20to%20increase>

patient-reported lived experience and formalised assessments of fatigue.

- Patients should track symptoms and energy levels through logs, diaries and/or wearable tech to build evidence about their progress and identify early warning signs.
- Establish a baseline for maximum activity levels, plan activities with rest breaks, gradually increase activity by about 10% weekly (if tolerated), and monitor progress to adjust the plan accordingly.

### *Additional Resources*

For more information and deeper insights, please explore the following resources:

#### **Websites:**

**[Long COVID Physio:](#)** This website is a valuable resource for people with Long COVID, offering education, support, and advocacy. It features information on common symptoms, self-management strategies, and pacing techniques to help manage energy levels. The site is patient-led, ensuring accessibility and inclusivity for diverse audiences. It also engages in research and advocacy efforts to improve care guidelines and policies related to Long COVID.

**[Fatigue Learning Module \(Austin Health\):](#)** This

website provides an interactive learning module focused on Long COVID, featuring educational content, resources, and strategies for managing symptoms. It aims to enhance understanding of Long COVID and support individuals in navigating their experiences, promoting effective self-management and recovery through engaging and accessible information.

**Activity & Rest Module (Austin Health):** The Activity and Rest Module by Austin Health is an interactive online resource designed to educate individuals about managing energy levels through effective pacing strategies. It provides practical guidance on balancing activity and rest, helping users understand how to optimise their daily routines for better health and well-being.

**ME Action:** This website is global advocacy platform for individuals affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). It focuses on raising awareness, promoting research, and improving care for ME/CFS patients. Key initiatives include organising protests like #MillionsMissing, providing educational resources, and fostering community engagement through projects like MEpedia, a crowd-sourced knowledge base. The organisation emphasises patient empowerment and aims to ensure better recognition and support for those living with the condition.

- [Pacing and management guide for ME/CFS](#)
- [Pacing and management guide from paediatric ME/CFS and Long COVID](#)

[The Royal College of Occupational Therapists](#)

**(RCOT):** The Royal College of Occupational Therapists (RCOT) is a UK professional body advocating for occupational therapy. It supports members through resources, career development, and practice guidance. RCOT emphasises diversity and inclusion while promoting the profession's value in improving health outcomes, and has a strategic plan for workforce expansion through 2035.

- [Post viral fatigue and energy conservation](#)
- [How to manage post-viral fatigue after COVID-19 - Practical advice for people who have been treated in hospital](#)
- [How to manage post-viral fatigue after COVID-19 - Practical advice for people who have recovered at home](#)
- [How to conserve your energy](#)

### **Consumer Lived Experience**

#### **[ME Support: Navigating ME/CFS and Long COVID:](#)**

Features the perspectives of seven individuals living with Long COVID and five experts in the field. Through recorded interviews, the site delves into the personal journeys of these individuals, providing in-depth insights into how Long COVID affects their daily lives and routines. This resource highlights the unique challenges and adaptations they face, underscoring the importance of understanding their experiences in developing effective support strategies.

### **Podcast**

**[Action for Me:](#)** This podcast episode features a consumer sharing her lived experience of living with

Long COVID. She discusses her journey in collaborating with health professionals to identify effective interventions and strategies tailored to her needs. Additionally, she offers valuable tips for supporting individuals with Long COVID, drawing from her personal insights and experiences.



## PART III

# ENVIRONMENTAL FACTORS

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

Environmental Factors are one of the categories of the International Classification of Function (ICF) and include “the physical, social and attitudinal environments in which people live and conduct their lives”<sup>1</sup>. These factors are considered from the perspective of the person with Long COVID. For example, seating in a public environment (i.e. park benches) may be considered a facilitator for people with Long COVID but a barrier for others if anti-homeless features have been included).

The five ICF chapter headings for environmental factors are listed below, and each contains a list of components (see [here](#) for more information).

- Products and technology
- The natural environment and human-made changes to the environment

1. World Health Organisation. (2023). Environmental Factors. Available at <https://icd.who.int/dev11/l-icf/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f1141487728>.

- Support and relationships
- Attitudes
- Services, systems and policies



# 3. Co-Produced Best Practice Principles for Working with People Experiencing Long COVID

*By Danielle Hitch & Sara Holton*

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

## Learning Objectives

After reading this chapter and completing the learning activities, you will:

- Reflect on your current assumptions about

what constitutes 'best care' for people with Long COVID.

- Review the concepts of 'best care' and 'best care practices' more broadly, including the tools available to translate them into practice.
- Self-assess your current approach to partnering with people experiencing Long COVID.
- Understand the co-design process used to develop best care principles for people with Long COVID.
- Identify and describe seven best practice principles in both plain language and clinical or professional terms.
- Complete an Action Plan to make improvements on working with people with Long COVID
- Translate your new knowledge about 'best care' to two personas and examine factors which influence individuals outcomes.

## Introduction

Health professional and other caregiver (such as family) generally want to provide the best care possible to every person with Long COVID. In some practice areas, there are clear guidelines about best care practices built on an established evidence base – we know what works, for whom and in what circumstances. Sadly, that isn't the case regarding recovery from COVID-19 infection and Long COVID at the moment. As

stated in the previous chapter, “we are currently building the plane while flying it”.

This chapter provides an overview of best care and best care practices for people with Long COVID in healthcare. The co-design process employed to develop best care principles for people with Long COVID is then described in detail to provide a template for other services wishing to do the same with their local communities. A key output of this process was seven best practice principles that reflect what best care looks like to people with Long COVID. These are presented in both plain language and clinical or professional terminology.

The chapter includes several reflection and learning activities to help you translate the best care principles into your practice. These activities consider your current understanding of best care in Long COVID, a self-assessment of your current approach to partnering with people experiencing Long COVID, the development of an Action Plan to improve your or your services work with these patients and the opportunity to apply your new understanding to two of the personas in this book. This chapter will provide you with an overview of what ‘best practice’ looks like, and there will be many opportunities to dive more deeply into the substance of each principle in other chapters throughout this book.

## Reflection (10 mins)

What are your current assumptions about best care practices in the care of people with Long COVID?

- Who do you think it includes?
- Who delivers or receives it?
- Where does it happen?
- When does it happen?

Brainstorm your ideas with colleagues to highlight different approaches to this question, or show your ideas to someone else and discuss.

## Providing the best care for people living with Long COVID.

Before considering best care principles, it is worth reflecting on what we mean by 'best care'. The concept of best care refers to the highest possible standard of care that a patient can receive, including accessibility, personalisation and effectiveness. Best care is described as working in partnership with colleagues and patients to achieve high-quality care that is safe, person-centred, right and coordinated<sup>1</sup>. Best care is closely linked to patient expectations; however, patients are just one of many perspectives on what is considered best care<sup>2</sup>. Best care is

1. Western Health. (2019). Best Care Framework June 2019. Available from [www.westernhealth.org.au/Careers/Documents/Best%20Care%20Framework%20document.pdf](http://www.westernhealth.org.au/Careers/Documents/Best%20Care%20Framework%20document.pdf)
2. Krause, F., Boldt, J. (2018). Understanding Care: Introductory Remarks. In: Krause, F., Boldt, J. (eds) Care in Healthcare. Palgrave Macmillan

often characterised as being founded on specific values, including compassion, excellence, and respect for a patient's dignity and autonomy <sup>3</sup>. Another related (but distinctive) concept relevant to best care is value-based care, which asserts that best care must provide good financial value to both the patient and the broader community, thereby ensuring limited healthcare resources are being allocated to the greatest possible benefit <sup>4</sup>. The video below explains the concept of value-based healthcare, which is increasingly perceived as being synonymous with the best care and the promotion of equity.



*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#oembed-1>*

Video by [Australian Centre for Value-Based Health Care](#), via YouTube

Given the novelty of COVID-19 and the complexity of Long COVID, providing the best care for patients will be extremely challenging for some time. The lack of certainty about which interventions are effective and acceptable in supporting an optimal recovery from COVID-19 can be a source of moral distress and frustration for health professionals and other

3. Halligan A. (2008). The importance of values in healthcare.

Journal of the Royal Society of Medicine, 101(10), 480–481.

4. Rech Ramos, P. (2021). Value-Based Healthcare. IntechOpen.

doi: 10.5772/intechopen.93378

caregivers. Moral distress occurs when it is impossible for health professionals and other caregivers to act in a way they consider ethically correct or provide best care <sup>5</sup>. International studies have highlighted that many healthcare workers are currently experiencing poor mental health, and their mental health may be deteriorating due to the sustained pressure of the COVID-19 pandemic <sup>6 7</sup>. Healthcare workers face potential barriers to providing best care, including sudden changes in clinical practice as new waves of COVID-19 infection arrive and the overall extreme pressure healthcare systems continue to experience. Health professionals and other carers are also, of course, members of the general community and have, therefore, also experienced the negative impacts of the pandemic, such as concerns about family members becoming infected, managing school-aged children who are learning remotely or experiencing job insecurity.

5. Beltrao, J.R., Figueiredo, B., Sachetim, G., Aihara, L., Aihara, L., & Corradi-Perini, C. (2022). Healthcare professional's moral distress during the COVID-19 pandemic: an integrative review. *Research, Society and Development*, 11(14), e281111436435.
6. Hitch, D., Booth S., Wynter K., Said, C., Haines, K., Rasmussen, B., & Holton S. (2023) Worsening general health and psychosocial wellbeing of Australian hospital allied health practitioners during the COVID-19 pandemic. *Australian Health Review*, 47, 124-130.
7. Gholami, M., Fawad, I., Shadan, S., Rowaiee, R., Ghanem, H., Hassan Khamis, A., & Ho, S. B. (2021). COVID-19 and healthcare workers: A systematic review and meta-analysis. *International journal of infectious diseases : IJID : official publication of the International Society for Infectious Diseases*, 104, 335–346.

**“The experience at the hospital was good. There were a few misses here and there, but it wasn’t over the top or anything. They were just doing the best they could” (Female, 40-49 years)**

People with Long COVID understand the restrictions and challenges their healthcare workers are facing. While many people with Long COVID are understandably frustrated about the slow pace of progress in identifying effective treatments and therapies, they also understand that Long COVID

is a novel condition. Therefore, healthcare professionals are still learning about and researching the condition and the best ways to provide care for people with Long COVID. A consistent theme from the participants in an ongoing Australian qualitative study <sup>8</sup> has been they wish healthcare workers would be honest about the limits of their knowledge. Perceptions that healthcare workers are overstating their expertise in this area can particularly damage therapeutic relationships. “I don’t know, but I’ll try to find out for you” is a perfectly acceptable answer.

*“It was so similar to when I had it with Guillain-Barre that I was just like, ‘I knew it.’ They’re just like,*

8. Hitch, D., Deféin, E., Lloyd, M., Rasmussen, B., Haines, K., & Garnys, E. (2023). Beyond the case numbers: Social determinants and contextual factors in patient narratives of recovery from COVID-19. *Australian and New Zealand Journal of Public Health*, 47(1), 100002.

*'Oh no, no, you don't have it.' I'm just like, 'How can you tell? You didn't run any tests?'. So yes, they don't rank high up there on the hospitals I go to. (Female, 50-59).*

## Tools to support best care in practice.

To deliver the best care to people with Long COVID, we need to adopt the best practices. Best practice is a broad concept, and there is no single accepted definition. However, most definitions emphasise that best practice should be based on the latest scientific evidence, supplemented by clinical expertise and supported by resources such as formalised guidelines, protocols and processes<sup>9</sup>. As stated by Hamilton, “Best practice refers to the clinical practices, treatments, and interventions that result in the best possible outcome for the patient and the health care facility providing those services”<sup>10</sup>. Best practice can occur in any area of healthcare, including health promotion, prevention, acute treatment, management of chronic conditions and quality assurance measures (such as patient safety and infection control).

9. Hamilton, K. (2011). What Constitutes Best Practice in Healthcare Design? Health Environments Research & Design Journal (HERD) (Vendome Group LLC), 4(2), 121–126.
10. Hamilton, K. (2011). What Constitutes Best Practice in Healthcare Design? Health Environments Research & Design Journal (HERD), 4(2), 121–126.



While the role of patients has become more explicit in definitions of evidence-based practice in recent years, recognition of their contribution to quality healthcare is yet to be included in formal definitions of 'best practice'. Healthcare system perceptions of best practices are still founded on the expertise offered by research and clinicians. Patient involvement is most often found at the direct care level as they participate in their own healthcare treatment<sup>11</sup>. However, changes in the way patients are included in healthcare systems worldwide have the potential to enable our aspirations of providing 'best care' to become a reality in everyday practice.

## Reflection (60 mins)

- Read pages 7 to 29 of the Safer Care Victorian [Partnering in Healthcare](#) Framework.
- Review the [Partnering in Healthcare Self-Assessment Tool](#), and choose one of the domains. Evaluate your current practice with people experiencing Long COVID and identify opportunities to further develop your partnerships. *Please note: You do not have to share your assessment with anyone, and only*

11. Horvat, L. (2019). Partnering in healthcare for better care and outcomes. Safer Care Victoria, State Government of Victoria: Melbourne.

*services in the Australian state of Victoria have the option (if they wish) of sharing it with Safer Care Victoria.*

This framework is one of many that describe patient engagement. You may choose to complete this activity using another framework that better reflects the needs of your service or your local community. Regardless of the framework you choose, the Self-Assessment Tool above provides guidance on the key prompts and questions you should consider.

The COVID-19 pandemic has highlighted both the potential and fragility of consumer and community engagement in health service and evidence base development, with the initial wave of cases provoking a 58% drop in projects involving patients in the United Kingdom alone<sup>12 13</sup>. This was reflected in the Rehabilitation Research Framework for Patients with COVID-19 produced by WHO and Cochrane Rehabilitation in May 2020, which was drafted without the input of patients, families, or representatives of consumer organisations<sup>14</sup>. The

12. Denegri, S., & Starling, B. (2021). COVID-19 and patient engagement in health research: What have we learned? Canadian Medical Association Journal, 193(27), E1048-E1049.
13. Health Research Authority. (2021). Public involvement in a pandemic: lessons from the UK COVID-19 public involvement matching service. London: National Health Service
14. Negrini, S., Mills, J., Arienti, C., Kiekens, C., & Cieza, A. (2020). "Rehabilitation Research Framework for Patients With COVID-19" Defined by Cochrane Rehabilitation and the World

exclusion of consumers (and the broader community) from COVID-19 research is counterproductive, given how important trust in scientific guidance is to reducing the spread of COVID-19<sup>15</sup>, and the strong influence of politics and culture on how both patients and the broader community make sense of Long COVID and the pandemic overall<sup>16</sup>.

## Co-Producing Best Practice Principles for Working with People Experiencing Long COVID.

More recently, there has been improvement in patient involvement in COVID-19 research and service development as the world has adjusted to its 'new normal'. Both the Australian

Health Organization Rehabilitation Programme. Archives of Physical Medicine & Rehabilitation, 102, 1424-1430.

15. Pagliaro, S., Sacchi, S., GPacilli, M., Brambilla, M., Lionetti, F., Battache, K., Bianchi, M., Biella, M., Bonnot, V., Boza, M., Butera, F., Ceylan-Batur, S., Chong, K., Chopova, T., Crimston, C., Álvarez, B., Cuadrado, I., Ellemers, N., Formanowicz, M., Graupmann, V., Gkinopoulos, T., Jeong, E., Jasinskaja-Lahti, I., Jetten, J., Bin, K., Mao, Y., McCoy, C., Mehnaz, F., Minescu, A., Sirlopú, D., Simić, A., Travaglino, G., Uskul, A., Zanetti, C., Zinn, A., & Zubieta, E. (2021). Trust predicts COVID-19 prescribed and discretionary behavioral intentions in 23 countries. Plos ONE, 16(3), e0248334.
16. Campbell, S. (2021). Interpretation of illness and COVID-19. The Open Journal of Occupational Therapy, 9(4), 1-4.

<sup>17</sup> and United Kingdom <sup>18</sup> Clinical practice guidelines for the clinical care of people with COVID-19 include contributions from consumer panels. Patient-led research began early in the pandemic by groups such as Body Politic <sup>19</sup> and is ongoing. Nevertheless, patient-led or co-designed models of care, quality standards or principles for health services remain a rarity despite repeated calls for their development in the literature <sup>20 21</sup>.

### *Existing Best Practice Guidelines for People with Long COVID*

Ladds et al. <sup>22</sup> proposed clinical quality standards for healthcare

17. National Covid-19 Clinical Evidence Taskforce. (2022). Caring for people with COVID-19: Living Guidelines. Available from <https://covid19evidence.net.au/#living-guidelines>.
18. National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), & Royal College of General Practitioners (RCGP). (2022). COVID-19 rapid guideline: Managing the long-term effects of COVID-19. Version 1.14. In. London: NICE, SIGN, RCGP.
19. McCorkell, L., Assaf, G., Davis, H., Wei, H., & Akrami, A. (2020). Patient-Led Research for COVID-19: Embedding Patients in the Long COVID Narrative. Available from <https://osf.io/n9e75/>
20. Hensher, M., Angeles, M., de Graaff, B., Campbell, J., Athan, E., & Haddock, R. (2021). Managing the long-term health consequences of COVID-19 in Australia. In. Canberra Deeble Institute for Health Policy Research.
21. McClymont, G. (2021). The role of patients and patient activism in the development of Long COVID policy. *Cambridge Journal of Science & Policy*, 2(1), 1-12.
22. Ladds, E., Rushforth, A., Wieringa, S., Taylor, S., Rayner, C.,

services about the care of people with Long COVID based on the findings of a study about healthcare workers experiencing this syndrome after infection in the initial 2020 pandemic waves. This qualitative study (n=114) explored the lived experience of these consumers and their preferences around the support and services that would help their recovery. The participants emphasised a need for patient-centred and personalised care, early identification and intervention, support for self-management and access to multidisciplinary treatment and rehabilitation. They also highlighted the importance of involving lived experience experts and their carers in developing future services for people with Long COVID. The table below summarises the clinical quality principles developed from the researcher's analysis of these interviews.



An interactive H5P element has been excluded from this version of the text. You can view it online here:

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#h5p-24>

This research and the resulting principles have made a valuable contribution to our understanding of the lived experiences and needs of Long COVID patients. The authors were the first to suggest the importance of underpinning care principles when developing and implementing new health services to meet the needs of people with Long COVID. Although the study had a relatively large sample size and explored consumer preferences, healthcare workers are a very specific group of

Husain, L., & Greenhalgh, T. (2021). Developing services for long COVID: lessons from a study of wounded healers. *Clinical Medicine*, 21(1), 59-65.

people living with Long COVID. They tend to be more highly educated and health literate and have better resources. Their status as 'insiders' could also be interpreted as a double-edged sword; they may be better placed to recommend workable quality standards but could also unintentionally perpetuate existing limitations within the system. The quality standards developed in the research were also initially drafted by the research team before being presented to the consumers for comment and feedback, which reflects a consultation ( 'doing for') rather than a co-design or co-production ('doing with') approach to patient engagement<sup>23</sup>. In terms of co-production, 'doing with' is far preferable to 'doing for'.

### *The Process of Co-Producing with Lived Experience Experts*

In 2021, a team of researchers and people with Long COVID (lived experience experts) worked together to co-produce Long COVID best care practice guidelines. Co-production of these best care principles occurred as part of a research project which received ethics approval from an Australian metropolitan public health service (Western Health, Melbourne) (HREC/2020/WH/70312). The project was undertaken in partnership with the Institute of Health Transformation at Deakin University, Geelong, which provided a seeding grant to support its completion. This study utilised a co-design process that incorporated and built upon existing

23. Australian Mental Health Commission (2017). Consumer and carer engagement: A practical guide. available from [www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide](http://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide).

evidence to support rapid translation into practice. The co-design process was founded on the principles of Experience-Based Co-Design (EBCD) <sup>24</sup> and collected both quantitative (numerical) and qualitative (text) data <sup>25</sup>. While engagement with consumers from the beginning of the co-design process is considered best practice <sup>26</sup>, the abbreviated approach adopted ensured the feasibility of the study in the context of Australia's third wave of the COVID-19 pandemic (September – December 2021) and the redeployment of co-design team members to frontline COVID-19 response duties. Each step of the co-design process is described in greater detail below.

As shown in the e-booklet below, the co-production process included contributions from multiple stakeholder groups and multiple data sources. The following description is intended to provide an overview of the process, and more specific detail about each step is available from the authors upon reasonable request.



24. Dimopoulos-Bick, T., O'Connor, C., Montgomery, J., Szanto, T., & Fisher, M. (2019). "Anyone can co-design?": A case study synthesis of six experience-based co-design (EBCD) projects for healthcare systems improvement in New South Wales, Australia Patient Experience Journal, 6(2), Article 15.
25. Cresswell, J., & Plano Clark, V. (2018). Designing and conducting mixed methods research (3rd ed.). SAGE.
26. Fylan, B., Tomlinson, J., Raynor, D. K., & Silcock, J. (2021). Using experience-based co-design with patients, carers and healthcare professionals to develop theory-based interventions for safer medicines use. Research in Social and Administrative Pharmacy, 17(12), 2127-2135.



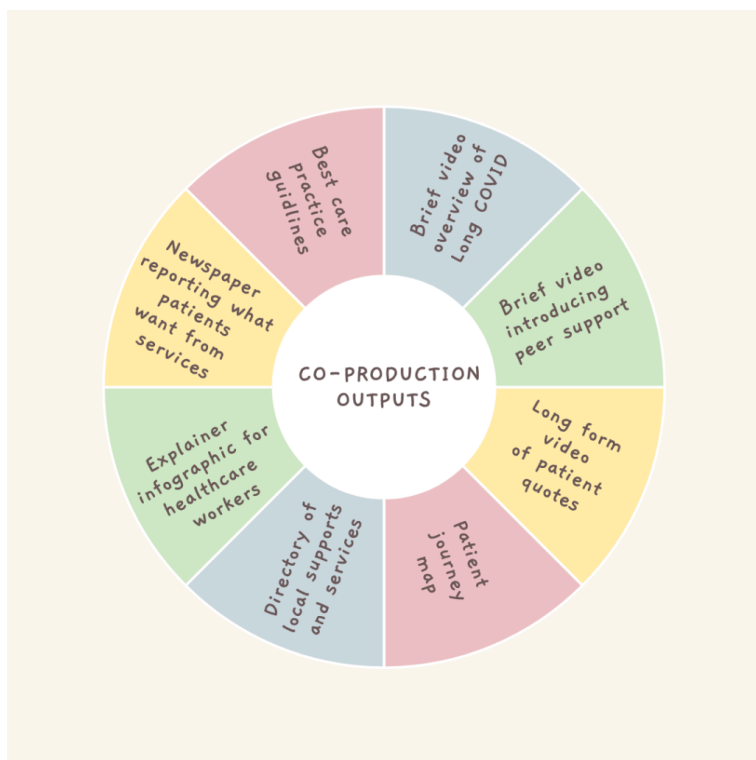
*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#h5p-26>

The best practice principles described here were just one of several outputs from this co-design process, all of which were consciously designed to be accessible and embedded in the evidence gathered by the team and available in the broader literature.





“Co-Production Outputs” by [Danielle Hitch](#) is licensed under [CC BY 4.0](#).

Throughout the co-design process, continual data analysis allowed the timely review and discussion of findings to inform the next step. All quantitative data from the outcome measures and the healthcare worker survey were analysed using SPSS (Version 27)<sup>27</sup> and evaluated with descriptive statistics. Reflexive thematic analysis was employed to analyse

27. IBM Corp. (2020). IBM SPSS Statistics for Windows (Version 27.0) [Computer software]. IBM Corp.

the patient interviews and qualitative healthcare worker survey data, following the methodology outlined by Braun and Clarke<sup>28</sup>. The Dedoose online platform<sup>29</sup> was used to manage the large amount of quantitative and qualitative data collected during the co-design process, which supported interrogation between the quantitative and qualitative findings. Comparative analysis between all data sources continued iteratively throughout the study to support triangulation, ensuring rigour and providing coherence to the overall findings.

## **Communicating Co-Produced Best Practice Principles**

The co-design team frequently reflected on language and held the shared belief that ‘words matter’. These discussions prompted the research team to reflect on the concept of health literacy, which is usually defined as a patient’s ability to access, understand, and use information to make informed decisions about their health<sup>30</sup>.

28. Braun, V., & Clarke, V. (2021). *Thematic Analysis: A Practical Guide*. London: Sage
29. Dedoose Version 9.0.17, cloud application for managing, analyzing, and presenting qualitative and mixed-method research data (2021). Los Angeles, CA: SocioCultural Research Consultants, LLC [www.dedoose.com](http://www.dedoose.com).
30. Peerson, A., & Saunders, M. (2009). Health literacy revisited: what do we mean and why does it matter? *Health Promotion International*, 24(3), 285–296,

**“At the moment, it’s Facebook groups, and I don’t know what these people are saying ... I don’t know if it’s, you know, all wacky” (Female, 30-39 years).**

Improving patient health literacy requires a transdisciplinary approach to care and promoting health literacies<sup>31</sup> across multiple formats, including print, oral and digital communications<sup>32</sup>. Some approaches to health literacy also involve consumer education about

critically appraising health information from online forums, which was also commented upon by one of the research participants. However, most current health literacy approaches reflect a ‘deficit’ approach, where information generally flows from one direction (i.e. from health experts to the patient). This approach emphasises a gap between the valued (and sometimes paternalistic) knowledge of health experts and the less knowledgeable patients. From this perspective, it is the patients’ responsibility to educate themselves and bridge the gap<sup>33</sup>. This approach to communicating our best practice principles seemed at odds with the overall values and philosophy of co-production.

31. Mackert, M., Champlin, S., Su, Z., & Guadagno, M. (2015) The Many Health Literacies: Advancing Research or Fragmentation? *Health Communication*, 30(12), 1161-1165,
32. Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, 303–305.
33. Stocklmayer, S. (2012). Engagement with science: Models of science communication. In: Gilbert JK, Stocklmayer S, editors. *Communication and engagement with science and technology: Issues and dilemmas - A reader in science communication*. London: Taylor & Francis Group, 19-38.

The finalised best practice principles, therefore, reflected a dialogue approach to science communication, which engages with context and encourages a collaborative approach to translate the findings into practice<sup>34</sup>. Dialogue approaches are designed to encourage symmetrical and mutual communication between researchers, healthcare workers and lived experience experts by including non-scientific perspectives and not assuming scientific authority is privileged<sup>35</sup>. The producers of new knowledge (in this case, the co-design team) and the people who will use it in practice (healthcare workers) are interdependent, and successful dialogues depend on both the sender and the receiver.

In this spirit, the principles are expressed in everyday language and then translated into 'professional' language to educate healthcare workers on how they can be translated to their practice. The lived experience experts in the co-design team emphasised the need for plain language principles as an authentic expression of the voice of patients. While jargon and technical language are necessary for effective communication in some situations, the description of general behaviour offered by these principles is appropriately conveyed in the everyday language of patients. By privileging plain language, these best practice principles, therefore, flip traditional approaches to health literacy and offer an opportunity for health professionals and other carers to improve their 'patient literacy'.

34. Trench, B. (2008). Towards an analytical framework of science communication models. In: Cheng D, Claessens M, Gascoigne T, Metcalfe J, Schiele B, Shi S, editors. *Communicating science in social contexts*. Dordrecht: Springer, 119-135.
35. Gross, A.G. (1994). The roles of rhetoric in the public understanding of science. *Public Understanding of Science*, 3(1), 3-23.

## The Principles.

Seven best practice principles were identified and developed by the co-design team, which reflect the preferences of people with Long COVID regarding best care practices. The following flash cards will introduce you to the best care practice principles in plain language (front) and their related professional terms (back).



An interactive H5P element has been excluded from this version of the text. You can view it online

here:

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#h5p-28>

The following poster summarises the best care principles in plain language and reflects the inclusive approach that lay at the foundation of their development.



*“Best care principles when working with people experiencing Long COVID” by [Danielle Hitch](#) is licensed under [CC BY 4.0](#).*

## Reflection (20 mins)

Many of the 'big issues' in modern healthcare have a direct relationship with these best care principles. Consider what they 'look like' in your own practice or the practices of your service. Use a copy of the table below to identify what you (or others) might say and do that reflects the influence of these issues ([Downloadable Table Template](#)). You may use dot points, and each response should be brief. It's OK if you don't have a response for some of these issues .... these may be aspects of the principles you choose to develop in the future.

*Please note: Not all health professionals diagnose as part of their role, and this term can be reworked as 'assessment error'.*

Principle	Healthcare Issues & Terminology	What do you (or others) say?	What do you (or others) do?
1	Comprehensive biopsychosocial assessment		
2	Diagnostic / assessment error		
2	Gaslighting		
3	Goal setting		
3	Outcome measures		
4	Integrated Care		
4	Care Co-Ordination		
5	Social Inclusion		
6	Evidence-Based Practice		
6	Evidence-Informed Practice		
7	Co-Production		
7	Person Centred Practice		

## How can I take ‘best care’ from aspiration to reality?

Now is the time to translate the best care practice principles into your own practice as a healthcare professional or other

caregiver. Every practice context is different, and undertaking a Strength, Weakness, Opportunities and Threats (SWOT) analysis will help you to identify internal and external factors that impact on your ability to provide best care to people with Long COVID. Please watch the following video to get an overview of how SWOT analyses can inform practice improvements.



*One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#oembed-2>*

“[SWOT Analysis](#)” by [DIY Toolkit – YouTube](#) is licensed under CC BY 3.0.

## Learning Activity

Complete the Action Plan template below which provides an opportunity to complete a SWOT analysis for each of the 7 principles of best care practice when working with people with Long COVID.

- The Action Plan can be completed either individually or as a group.
- No time guide has been provided for this activity as it can be completed in a number of



different ways. You may choose to complete all principles at once or select one or more to focus on.

- We would encourage you to consider the principles from both your individual perspective and the organizational perspective of your healthcare service. However, you may choose to only focus on one of these domains.
- The template is in an editable Word format, and each box can expand to include as much or as little detail as you wish. You can also download and save the template for future reference or updates.
- Please remember to correctly attribute this template whenever you refer to it in publications or presentations.

Please click here to download: [Best Care Principles Goals and Action Plan V1](#)

## Providing best care to people with Long COVID.

These best care principles can be modified or adapted to meet the needs of individual patients in many different ways. This process is part of their 'translation' to practice, and no two applications of these principles will be exactly the same due to variations in individual circumstances and needs. As you've seen in the learning activity above, the principles can be applied from the service provider's perspective to benchmark

current practices and identify opportunities for further development and improvements. They can also provide a foundation for vision or mission statements and for developing key performance indicators that articulate expected behaviours when working with people experiencing Long COVID.

However, best care principles can also be helpful for working with individual patients and families. The principles presented here were derived specifically from the lived experience of people with Long COVID, and the alignment of treatment plans could document and guide collaborative discussions with patients. For example, treatment plans could be supplemented by plain language summaries of the evidence available for a specific intervention or include a specific section about promoting social connections. Patient education resources could be developed for each of these principles as part of an overall model of care, which illustrates how these broad concepts inform specific goals or actions. Ensuring that patients know you or your service's commitment to these principles can also promote accountability, particularly if you encourage people with Long COVID to give you feedback about your performance against each of them.

## Learning Activity (30 mins)

Read the 'COVID-19' section of the personas of [Josh](#) and [Jen](#) (from Acute Infection to Current Situation).  
Using the worksheet below, note down aspects of their

lived experience that reflect each of the principles of best care practice.

- Can you identify areas of good practice? Were there also some examples of areas for improvement?
- What do you think the supports and services they access could do different in future?
- What factors do you think influenced the differences in their experiences? Could these factors be acted upon to promote better outcomes?

Please click here to download: [Applying Best Care Principles to Josh and Jen](#)

## Conclusion

Two perspectives on the question “What is Long COVID?” have been presented in this chapter – the current knowledge of healthcare researchers and practitioners and the lived experience expertise of patients. Clearly, this syndrome is far more than a collection of commonly co-occurring symptoms. The COVID-19 pandemic has been as much a social phenomenon as a global healthcare emergency, and the knowledge required to engage with its pervasive impact (including Long COVID) originates from multiple disciplines and ways and understanding<sup>36</sup>. Long COVID, in particular,

36. Leach, M. (2020). Pandemics are social phenomena,

highlights the complex and constant interplay between the multitude of biopsychosocial factors that influence health and well-being. No wonder researchers, healthcare practitioners and patients alike feel overwhelmed.

As highlighted in this chapter, Long COVID means different things to different people, and a 'one size fits all' approach cannot be applied. Our knowledge of Long COVID is evolving at lightning speed, with multiple new challenges and opportunities always emerging. Ultimately, Long COVID reminds us of the inherent unpredictability of life and spotlights the limitations of our knowledge. It forces us to confront the fact that sometimes we have to live with uncertainty and discomfort – for the foreseeable future, we will be 'flying the plane while building it'.<sup>37</sup> This chapter has, therefore, just scratched the surface of what there is to know and understand about Long COVID ... but we all have to start somewhere.

demanding breadth of expertise. WONKHE. Available at <https://wonkhe.com/blogs/pandemics-are-social-phenomena-demanding-breadth-of-expertise/>

37. Hitch, D. (2023). Long COVID: Why isn't anyone listening? Available at <https://insightplus.mja.com.au/2023/8/long-covid-why-isnt-anyone-listening/>

## For More Information

The following links will provide you with additional general information about Long COVID from credible sources. These listings are not exhaustive, and you are encouraged to seek out locally relevant information for your community.

- An analysis of supports and opposition to patient-centric culture during the pandemic: [Patient-centric culture and implications for patient engagement during the COVID-19 pandemic.](#)
- A commentary on the impact of the pandemic on co-production: [Co-Production during and after the COVID-19 pandemic: Will it last?](#)
- A video presenting both patient and physician perspectives on Long COVID: “[The Effects of Long COVID: A physicians and patient’s perspective](#)” by [Patient Safety Movement](#) is licensed under [CC BY3.0](#).



*One or more interactive elements has been excluded from this version of the text. You can view them online here:*

[https://oercollective.caul.edu.au/enabling-  
optimising-recovery-covid-19/?p=630#oembed-3](https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=630#oembed-3)

Please consider providing us some feedback via the following satisfaction survey, to help us ensure this textbook meets the needs of all readers: [Brief Feedback Survey – Best Care Practice Guidelines Chapter](#). If you have any additional feedback, suggestions or recommendations for improvement to this chapter, please email the editors at **[covidtextbook@deakin.edu.au](mailto:covidtextbook@deakin.edu.au)**.

# 4. Improving the Participation Gap: Physiotherapy for People Experiencing Long COVID

## **Improving the Participation Gap: Physiotherapy for People Experiencing Long COVID**

*By Kate Woodhead, Rita Kinsella,  
Karen Borschmann, Anne Holland,  
Janet Bondarenko & Danielle Hitch.*

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

You may find some material in multiple chapters (such as an introduction to common symptoms of

Long COVID) because we anticipate some readers will only access certain chapters. Please feel free to skip any material you are already familiar with.

## Learning objectives

After reading this chapter and completing the learning activities, you will be able to:

- Recognise the common symptoms of Long COVID
- Describe the assessment methods used in the management of Long COVID
- Demonstrate relevant assessment skills required to assist in the management of Long COVID
- Apply evidence-based exercise rehabilitation principles to design a program for patients presenting with Long COVID
- Plan a strategy for the self-management of a patient experiencing Long COVID



# Introduction

The longer-term impacts of Severe Acute Respiratory Syndrome Coronavirus 2 (**SARS-CoV-2**) or more commonly referred to as **COVID-19** infection have been described in the literature using varying terms, including “Long COVID”, “Long COVID-19”, “long-haul COVID”, “Post-Acute COVID-19”, “Post-COVID Conditions” and “Post-Acute Sequelae of SARS-CoV-2 infection (PASC)”<sup>12</sup>. The term Long COVID was first coined as a hashtag by a patient in Italy early in the pandemic<sup>3</sup> and is now widely recognised in the media, by patients, and in scientific literature<sup>4</sup>.

In an Australian context, the Parliamentary enquiry into Long COVID (2023) recommended that at this time the World Health

1. Centers for Disease Control and Prevention. (2022, December 16). Post-COVID Conditions: Information for Healthcare Providers. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html>
2. Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C., Sepulveda, R., Rebolledo, P. A., Cuapio, A., & Villapol, S. (2021). More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *Scientific Reports* 11, Article 16144. <https://doi.org/10.1038/s41598-021-95565-8>
3. Callard, F. & Perego, E. (2021). How and why patients made Long Covid. *Social Science Medicine* 238, 113426. <https://doi.org/10.1016/j.socscimed.2020.113426>
4. Crook, H., Raza, S., Nowell, J., Young, M., & Edison, P. (2021). Long covid – mechanisms, risk factors, and management. *BMJ (Clinical research ed.)*, 374, n1648. <https://doi.org/10.1136/bmj.n1648>

Organization's (WHO) definition of Long COVID be used clinically<sup>5</sup>.

5. House of Representatives Standing Committee on Health, Aged Care and Sport (2023). Sick and tired: Casting a long shadow. Inquiry into Long COVID and Repeated COVID Infections. Parliament of Australia. Canberra. Available at: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc\\_pdf/SickandtiredCastingalongshadow.pdf](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc_pdf/SickandtiredCastingalongshadow.pdf)

**Table 3.** A definition of post COVID-19 condition

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\* and 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.

**Notes:**

There is no minimal number of symptoms required for the diagnosis; though symptoms involving different organs systems and clusters have been described.

\*A full list of described symptoms included in the surveys can be found in Annexes 2 .

**Definitions:**

Fluctuate – a change from time to time in quantity or quality.

Relapse – return of disease manifestations after period of improvement.

Cluster – two or more symptoms that are related to each other and that occur together. They are composed of stable groups of symptoms, are relatively independent of other clusters, and may reveal specific underlying dimensions of symptoms (32).

Figure by  
World  
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n (WHO).  
WHO (2021).  
[A clinical  
case  
definition  
of post  
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For more information regarding the various definitions existing internationally please visit [Chapter 1. What is Long COVID?](#)

As the evidence continues to emerge regarding Long COVID, our understanding of the condition and the impact it has on

patients affected by it continues to grow<sup>67</sup>. With more than 760 million people having been diagnosed with COVID-19 worldwide since the beginning of the pandemic<sup>8</sup>, it stands to reason that we will continue to see an increasing number of people presenting to physiotherapy with symptoms and impairments that may be attributable to Long COVID either as a primary problem or a concurrent associated problem. As physiotherapists, regardless of our area of practice, it is vital we have an understanding of and awareness of Long COVID. This should include how to assess for, treat and manage the presenting impairments and/or limitations on activity participation of people experiencing Long COVID.

Whilst evidence continues to develop regarding the likely duration of the ongoing effects of an acute COVID-19

6. Centers for Disease Control and Prevention. (2022, December 16). Long COVID or Post-COVID Conditions.  
<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>
7. Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger C. L., Hodgson, C., Holland, A. E., Jones, A. Y.M., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice recommendations. *Journal of Physiotherapy*, 68, 8-25.  
<https://doi.org/10.1016/j.jphys.2021.12.012>
8. World Health Organization. (2023). WHO Coronavirus (COVID-19) Dashboard. [Data set]. Retrieved March 7, 2023, from <https://covid19.who.int>

infection<sup>91011</sup>, anecdotal and newer evidence suggests that some patients with impairments attributable to Long COVID

9. Hodgson, C.L., Higgins, A.M, Bailey, M.J., Mather, A.M., Beach, L., Bellomo, R., Bissett, B., Boden, I.J., Bradley, S., Burrell, A., Cooper, D.J., Fulcher, B.J., Haines, K.J., Hopkins, J., Jones, A.Y.M., Lane, S., Lawrence, D., van der Lee, L., Liacos, J., Linke, N.J., Marques Gomes, L., Nickels, M., Ntoumenopoulos, G., Myles, P.S., Patman, S., Paton, M., Pound, G., Rai, S., Rix, A., Rollinson, T.C., Sivasuthan, J., Tipping, C.J., Thomas, P., Trapani, T., Udy, A.A., Whitehead, C., Hodgson, I.T., Anderson, S.A., Neto, A.S. & The COVID-Recovery Study Investigators and the ANZICS Clinical Trials Group. (2021). The impact of COVID-19 critical illness on new disability, functional outcomes and return to work at 6 months: a prospective cohort study. *Crit Care*, 25, 382. <https://doi.org/10.1186/s13054-021-03794-0>
10. Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C., Sepulveda, R., Rebolledo, P. A., Cuapio, A., & Villapol, S. (2021). More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *Scientific Reports* 11, Article 16144. <https://doi.org/10.1038/s41598-021-95565-8>
11. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188>

improve over time<sup>1213</sup>. The specific timeline for recovery and symptoms experienced is however unique to each individual<sup>14</sup>.

The learning objectives included in this chapter were drawn from the results of a national Australian survey of 104 physiotherapists and physiotherapy students. A Pat Cosh Trust grant (administered by the Australian Physiotherapy Association) has enabled the development of this interactive chapter to support the optimal management of patients presenting with impairments who are recovering after COVID-19 infection: click [here](#) for more information about the development of the chapter. The content of the chapter has been drawn from international and national guidelines and peer-reviewed journal publications.

This chapter will cover the following topics:

12. Centers for Disease Control and Prevention. (2022, December 16). Long COVID or Post-COVID Conditions. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>
13. Gerlis, C., Barradell, A., Gardiner, N.Y., Chaplin, E., Goddard, A., Singh, S.J., & Daynes, E. (2022). The Recovery Journey and the Rehabilitation Boat – A qualitative study to explore experiences of COVID-19 rehabilitation. *Chronic Respiratory Diseases*, 19, 1-9. <https://doi.org/10.1177/14799731221114266>
14. Gerlis, C., Barradell, A., Gardiner, N.Y., Chaplin, E., Goddard, A., Singh, S.J., & Daynes, E. (2022). The Recovery Journey and the Rehabilitation Boat – A qualitative study to explore experiences of COVID-19 rehabilitation. *Chronic Respiratory Diseases*, 19, 1-9. <https://doi.org/10.1177/14799731221114266>

- [Impairments that may benefit from physiotherapy management](#)
  - Common symptoms
  - Episodic nature of Long COVID
  - Referrals to other health professionals
- [Assessment](#)
  - General assessment
  - General screening tools
  - Cardiorespiratory screening tools
  - Functional and exercise capacity tests
  - Quality of life
  - Psychosocial
  - Other
  - Putting it all together
- [Exercise-based rehabilitation for Long COVID](#)
  - Precautions and contraindications to exercise; an overview
  - Contraindications
  - Precautions
  - Symptom monitoring
  - Exertional oxygen desaturation and breathlessness
  - Heart rate and exercise
  - [Post-Exertional Symptom Exacerbation \(PESE\)](#)
  - Pacing and activity management
  - Heart Rate (HR) monitoring
  - Education and supported self-management
  - [Autonomic dysfunction](#)
  - Orthostatic intolerance
  - Postural Orthostatic Tachycardia Syndrome (POTS)
  - Self-management and exercise
  - Autonomic Conditioning Therapy (ACT)
- [Other physiotherapy treatment/s for Long COVID](#)
  - Pain management
  - Breathing Pattern Disorders (BPD)
  - Fatigue
- [Self-management for Long COVID](#)
- [Further information](#)

The content has been peer-reviewed and will be updated periodically as new evidence related to the physiotherapy management of Long COVID emerges.

## Impairments that may benefit from physiotherapy management

Long COVID is frequently described in the literature as being

“multi-dimensional, episodic and unpredictable”<sup>15</sup>. Presenting symptoms can vary widely from patient to patient<sup>16,17</sup>. Patients can present with overlapping or clustered symptoms, which may change or fluctuate over time<sup>18</sup>. Physiotherapists assist patients to improve their quality of life<sup>19</sup> and it has been well documented that the symptoms of Long COVID can have a significant detrimental impact on health and wellbeing<sup>20</sup>. As

15. Brown, D.A., & O'Brien, K.K. (2021) Conceptualising Long COVID as an episodic health condition. *BMJ Global Health*, 6, e007004. <https://doi.org/10.1136/bmjgh-2021-007004>
16. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188>
17. Michelen, M., Manoharan, L., Elkheir, N., Cheng, V., Dagens, A., Hastie, C., O'Hara, M., Suett, J., Dahmash, D., Bugaeva, P., Rigby, I., Munblit, D., Harriss, E., Burls, A., Foote, C., Scott, J., Carson, G., Olliaro, P., Sigfrid, L., & Stavropoulou, C. (2021). Characterising long COVID: a living systematic review. *BMJ Global Health*, 6(9), Article e005427. <http://dx.doi.org/10.1136/bmjgh-2021-005427>
18. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188>
19. Australian Physiotherapy Association. (2023) What Is Physio? Retrieved March 21, 2023, from <https://choose.physio/what-is-physio>
20. Bowyer, R. C. E., Huggins, C., Toms, R., Shaw, R. J., Hou, B., Thompson, E. J., Kwong, A. S. F., Williams, D. M., Kibble, M.,



a result of the wide range of symptoms that may be present, patients with Long COVID may experience varying degrees of impairment that can impact physical, cognitive, mental and emotional health, all of which may impact on their activities of daily living and participation in education and exercise<sup>21</sup>.

There is no one test to diagnose Long COVID, rather it is considered a diagnosis of exclusion<sup>22</sup>. It is also important to consider that presenting symptoms may be due to other factors such as underlying or pre-existing health conditions, complications from acute COVID-19 infection (such as **DVT** or **PE**), physical deconditioning that may have occurred after a long or complicated acute illness (such as post-intensive care syndrome), or even re-infection of COVID-19<sup>23,24</sup>. As primary

Ploubidis, G. B., Timpson, N. J., Sterne, J. A. C., Chaturvedi, N., Steves, C. J., Tilling, K. & Silverwood, R. J. (2023). Characterising patterns of COVID-19 and long COVID symptoms: evidence from nine UK longitudinal studies. *European Journal of Epidemiology* 38, 199-210. <https://doi.org/10.1007/s10654-022-00962-6>

21. Brown, D.A., & O'Brien, K.K. (2021) Conceptualising Long COVID as an episodic health condition. *BMJ Global Health*, 6, e007004. <https://doi.org/10.1136/bmjgh-2021-007004>
22. Centers for Disease Control and Prevention. (2022, December 16). Post-COVID Conditions: Information for Healthcare Providers. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html>
23. Centers for Disease Control and Prevention. (2022, December 16). Post-COVID Conditions: Information for Healthcare Providers. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html>
24. National COVID-19 Clinical Evidence Taskforce. (2023, May 30). Australian guidelines for the clinical care of people with

contact practitioners, physiotherapists should liaise with other members of the multidisciplinary team to further assist with refining medical diagnosis and differential diagnosis. Care should be adjusted as the team develops a greater understanding of the patient's presenting clinical signs and symptoms and their response to therapy deepens.

Also, health professionals who possess an understanding of the common presenting symptoms may assist patients with Long COVID to allay any associated fear or frustration that they may experience when interacting with the health system<sup>2526</sup>. The fears or frustrations that may be expressed by patients with Long COVID include but are not limited to<sup>27</sup>:

- Feeling let down or abandoned by healthcare services
- Feeling forgotten

COVID-19 (version 74.1). <https://app.magicapp.org/#/guideline/L4Q5An>

25. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188>
26. BATTERY, S., PHILIP, K.E.J., WILLIAMS, P., FALLAS, A., WEST, B., CUMELLA, A., CHEUNG, C., WALKER, S., QUINT, J.K., POLKEY, M.I., & HOPKINSON, N.S. (2021). Patient symptoms and experience following COVID-19: results from a UK-wide survey. *BMJ Open Resp Res*, 8, e0001075. <https://org/10.1136/bmjresp-2021-001075>
27. BATTERY, S., PHILIP, K.E.J., WILLIAMS, P., FALLAS, A., WEST, B., CUMELLA, A., CHEUNG, C., WALKER, S., QUINT, J.K., POLKEY, M.I., & HOPKINSON, N.S. (2021). Patient symptoms and experience following COVID-19: results from a UK-wide survey. *BMJ Open Resp Res*, 8, e0001075. <https://org/10.1136/bmjresp-2021-001075>

- Not feeling listened to
- Feeling like symptoms are not believed or dismissed
- Frustration related to symptoms being attributed to other issues such as anxiety

**“It has been an awful time and it made it worse when I felt that I wasn’t being believed about the symptoms. They put it down to anxiety disorder.”  
(Male, Age unknown)<sup>28</sup>**

These fears and frustrations may be reinforced by health professionals, family, friends and employers. Taking time to listen and validate a patient’s experience is an important part of the overall management of patients with Long COVID<sup>2930</sup>.

### *Common symptoms*

28. Buttery, S., Philip, K.E.J., Williams, P., Fallas, A., West, B., Cumella, A., Cheung, C., Walker, S., Quint, J.K., Polkey, M.I., & Hopkinson, N.S. (2021). Patient symptoms and experience following COVID-19: results from a UK-wide survey. *BMJ Open Resp Res*, 8, e0001075. <https://doi.org/10.1136/bmjresp-2021-001075>
29. National COVID-19 Clinical Evidence Taskforce. (2023, May 30). Australian guidelines for the clinical care of people with COVID-19 (version 74.1). <https://app.magicapp.org/#/guideline/L4Q5An>
30. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188>



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Symptoms of Long COVID can affect all body systems. **SARS-CoV-2** enters the body via the angiotensin-converting enzyme 2 (ACE-2) receptor<sup>31</sup>. These receptors are located on cells throughout the body, giving the virus the capacity to infect and damage cells within multiple organs, which is reflected in the large variety and differing of symptoms that people with Long COVID may experience<sup>32,33</sup>.

For further information related more broadly to Long COVID

31. Crook, H., Raza, S., Nowell, J., Young, M., & Edison, P. (2021). Long covid – mechanisms, risk factors, and management. *BMJ (Clinical research ed.)*, 374, n1648. <https://doi.org/10.1136/bmj.n1648>
32. Bowyer, R. C. E., Huggins, C., Toms, R., Shaw, R. J., Hou, B., Thompson, E. J., Kwong, A. S. F., Williams, D. M., Kibble, M., Ploubidis, G. B., Timpson, N. J., Sterne, J. A. C., Chaturvedi, N., Steves, C. J., Tilling, K. & Silverwood, R. J. (2023). Characterising patterns of COVID-19 and long COVID symptoms: evidence from nine UK longitudinal studies. *European Journal of Epidemiology* 38, 199-210. <https://doi.org/10.1007/s10654-022-00962-6>
33. Crook, H., Raza, S., Nowell, J., Young, M., & Edison, P. (2021). Long covid – mechanisms, risk factors, and management. *BMJ (Clinical research ed.)*, 374, n1648. <https://doi.org/10.1136/bmj.n1648>

and the symptoms, please visit [Chapter 1. What is Long COVID?](#)

Common symptoms of Long COVID<sup>3435</sup> that people presenting to physiotherapy may report include, but are not limited to:



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*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-35>

A systematic review of studies including over 47,000 patients has identified the three most common symptoms experienced

34. Centers for Disease Control and Prevention. (2022, December 16). Post-COVID Conditions: Information for Healthcare Providers. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html>
35. National COVID-19 Clinical Evidence Taskforce. (2023, May 30). Australian guidelines for the clinical care of people with COVID-19 (version 74.1). <https://app.magicapp.org/#/guideline/L4Q5An>

by people with Long COVID as being fatigue, cognitive and concentration impairment and shortness of breath<sup>36373839</sup>.

Further to this, a 2022 meta-analysis<sup>40</sup> including over 1.2 million patients from 22 countries reported on the prevalence

36. Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C., Sepulveda, R., Rebolledo, P. A., Cuapio, A., & Villapol, S. (2021). More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *Scientific Reports* 11, Article 16144. <https://doi.org/10.1038/s41598-021-95565-8>
37. Michelen, M., Manoharan, L., Elkheir, N., Cheng, V., Dagens, A., Hastie, C., O'Hara, M., Suett, J., Dahmash, D., Bugaeva, P., Rigby, I., Munblit, D., Harriss, E., Burls, A., Foote, C., Scott, J., Carson, G., Oliara, P., Sigfrid, L., & Stavropoulou, C. (2021). Characterising long COVID: a living systematic review. *BMJ Global Health*, 6(9), Article e005427. <http://dx.doi.org/10.1136/bmjgh-2021-005427>
38. Reyes Domingo, F., Waddell, L., Cheung, A., Cooper, C., Belcourt, V., Zuckerman, A., Corrin, T., Ahmad, R., Boland, L., Laprise, C., Idzerda, L., Khan, A., Morissette, K., & Garcia, A. (2021). Prevalence of long-term effects in individuals diagnosed with COVID-19: an updated living systematic review. *MedRxiv*. <https://doi.org/10.1101/2021.06.03.21258317>
39. Fernández-de-las-Peñas, C., Palacios-Ceña, D., Gómez-Mayordomo, V., Florencio, L.L., Cuadrado, M.L., Plaza-Manzano, G., and Navarro-Santana, M. (2021). Prevalence of post-COVID-19 symptoms in hospitalized and non-hospitalized COVID-19 survivors: A systematic review and meta-analysis. *European Journal of Internal Medicine*, 92, 55-70. <https://doi.org/10.1016/j.ejim.2021.06.009>
40. Global Burden of Disease Long COVID Collaborators. Estimated Global Proportions of Individuals With Persistent Fatigue, Cognitive, and Respiratory Symptom Clusters Following Symptomatic COVID-19 in 2020 and 2021. *JAMA*. 2022;328(16):1604–1615. <https://doi:10.1001/jama.2022.18931>

of three common Long COVID symptom clusters with these being respiratory symptoms (described as ongoing respiratory problems), fatigue symptoms (described as persistent fatigue with bodily pain or mood swings) and cognitive symptoms (and related cognitive problems).

## Key message

Long COVID is a “diagnosis of exclusion”<sup>41</sup>. It is important to consider all presenting symptoms and impairments and the potential or likely underlying cause of these.

The role of the physiotherapist is to assess for and manage the symptoms and impairments, regardless of a formal diagnosis of Long COVID. As primary contact practitioners, physiotherapists may also assist the multidisciplinary team in refining the diagnosis of Long COVID or the diagnosis of other non-Long COVID conditions.

41. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved March 7, 2023 from <https://www.nice.org.uk/guidance/ng188> . Pg 42.

## Episodic nature of Long COVID



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Symptoms not only vary, but may also fluctuate and people with Long COVID can experience 'false recovery'<sup>42</sup>. The uncertainty and unpredictability of the future for patients with Long COVID can be a significant source of distress and may manifest in newly diagnosed or exacerbation of pre-existing psychological problems, particularly anxiety<sup>43</sup>.

42. Buttery, S., Philip, K.E.J., Williams, P., Fallas, A., West, B., Cumella, A., Cheung, C., Walker, S., Quint, J.K., Polkey, M.I., & Hopkinson, N.S. (2021). Patient symptoms and experience following COVID-19: results from a UK-wide survey. *BMJ Open Resp Res*, 8, e0001075. <https://doi.org/10.1136/bmjresp-2021-001075>

43. Buttery, S., Philip, K.E.J., Williams, P., Fallas, A., West, B., Cumella, A., Cheung, C., Walker, S., Quint, J.K., Polkey, M.I., & Hopkinson, N.S. (2021). Patient symptoms and experience following COVID-19: results from a UK-wide survey. *BMJ Open Resp Res*, 8, e0001075. <https://doi.org/10.1136/bmjresp-2021-001075>



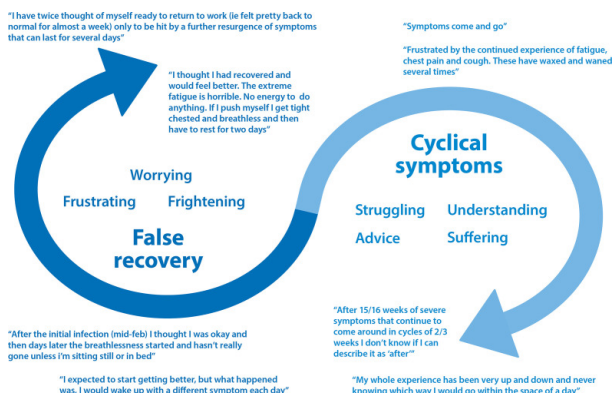


Figure by Buttery et al (2021). Licensed by BMJ Publishing Group (e001075). Buttery S, Philip KEJ, Williams P, Fallas A, West B, Cumella A, Cheung C, Walker S, Quint JK, Polkey MI, Hopkinson NS. [Patient symptoms and experience following COVID-19: results from a UK-wide survey](#). BMJ Open Respir Res. 2021 Nov;8(1):e001075. doi: 10.1136/bmjresp-2021-001075. © 2021 by the authors. This is an open-access article distributed in accordance with the Creative Commons Attribution Non

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## *Referrals to other health professionals*

Due to the wide variety of possible symptoms and impairments, multiple health professionals or teams may be required to assist in the ongoing management of patients experiencing Long COVID, particularly when symptoms are not related to respiratory or physical function<sup>44</sup>. Best

44. Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger C. L., Hodgson, C., Holland, A. E., Jones, A. Y.M., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice

practice management for patients with Long COVID would involve a multidisciplinary team either in a community setting or through Long COVID clinics<sup>45</sup>.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

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### **Long COVID Multidisciplinary Team.**

Photo by [Kampus Productions](#) from [Pexels](#).

## **Learning activity (10 mins)**

Complete the following multiple-choice quiz. Check

recommendations. Journal of Physiotherapy, 68, 8-25.

<https://doi.org/10.1016/j.jphys.2021.12.012>

45. National COVID-19 Clinical Evidence Taskforce. (2023, May 30).

Australian guidelines for the clinical care of people with COVID-19 (version 74.1). <https://app.magicapp.org/#/guideline/L4Q5An>

your answer by clicking the blue 'Check' box below before clicking the arrow across to go to the next question.



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Read the 'COVID-19' section of the persona of [Jarrod](#) and consider the questions below:

Do you feel Jarrod would require referral to other services?

Which other services might you refer Jarrod to?



**Jarrod Micallef.** Photo by [Tima Miroshnichenko](#) from [Pexels](#).

## Assessment

Assessment and the use of outcome measures are important to help determine whether a specific physiotherapy intervention is appropriate and its effectiveness, once

implemented, as part of the overall management of the patient. . Patients with

**Currently there are  
no tests or tools that  
have been  
recommended to  
confirm the  
diagnosis of Long  
COVID<sup>464748</sup>**

46. Allard, N., Miller, A., Morgan, M., & Chakraborty, S., (2022). Post-COVID -19 syndrome/condition or long COVID: Persistent illness after acute SARS CoV-2 infection. *AJGP*, 51 (12). Pp 952-957. <https://doi.org/10.31128/AJGP-05-22-6429>
47. House of Representatives Standing Committee on Health, Aged Care and Sport (2023). Sick and tired: Casting a long shadow. Inquiry into Long COVID and Repeated COVID Infections. Parliament of Australia. Canberra. Available at: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB0000006/toc\\_pdf/SickandtiredCastingalongshadow.pdf/footnote](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB0000006/toc_pdf/SickandtiredCastingalongshadow.pdf/footnote) Physiotherapy assessment in the patient with symptoms suggestive of Long COVID should include a comprehensive history, including screening for the presence of any red flags (e.g., prior overlooked conditions such as malignancy, or complications of acute COVID-19 such as thromboembolic events, myopericarditis, dysrhythmias, seizures or encephalitis)[footnote]Yelin, D., Moschopoulos, C.D., Margalit, I., Gkrania-Klotsas, E., Landi, F., Stahl, J-P., & Yahav, D. (2022). ESCMID rapid guidelines for assessment and management of long COVID. *Clinical Microbiology and Infection*, 28 (7), 955-972. <https://doi.org/10.1016/j.cmi.2022.02.018>
48. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.

concerning red flags, particularly if sinister pathology is suspected, should be referred onwards in a timely fashion. The goal of the patient interview should be to identify the severity of any symptoms and the impact these have on the quality of life and daily activities for the individual<sup>49</sup>. Various screening and assessment tools may be used to assist in this process. In addition, a symptom-based objective assessment should be undertaken where indicated, noting that once again there is no "one size fits all" set of outcome measure or tests for people experiencing Long COVID due to the wide and varying symptoms and their severity<sup>50</sup>.

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

49. Yelin, D., Moschopoulos, C.D., Margalit, I., Gkrania-Klotsas, E., Landi, F., Stahl, J-P., & Yahav, D. (2022). ESCMID rapid guidelines for assessment and management of long COVID. *Clinical Microbiology and Infection*, 28 (7), 955-972.

<https://doi.org/10.1016/j.cmi.2022.02.018>

50. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved April 18, 2023 from

<https://www.nice.org.uk/guidance/ng188>

**Table 3**

Assessment that may be considered by physiotherapists for patients with COVID-19 during transitions of care: ICU discharge<sup>a</sup>, hospital discharge<sup>b</sup> and 6 to 8 weeks after COVID-19 infection<sup>c</sup>.

Clinical area	Assessment items
Respiratory	Oxygen therapy requirements SpO <sub>2</sub> at rest and with exercise Dyspnoea at rest and with exertion Cough Presence of sputum and indications for airway clearance techniques
Physical	Autonomic dysfunction and orthostatic intolerances Post-exertional symptom exacerbation Muscle strength Physical function Exercise capacity/endurance (eg, 6-minute walk test) Level of mobility, walking aids required, walking distance and assistance required Balance Safety on stairs Ongoing rehabilitation needs Pain Pelvic floor and continence <sup>183</sup>
Other	Fatigue – activity-related or general malaise Sleep Delirium Cognitive function, including memory and concentration Social supports Return to work, family roles and recreational activities Consider referral to other healthcare professionals if indicated

SpO<sub>2</sub> = oxyhaemoglobin saturation.

<sup>a</sup> Clinical handover should occur with the ward staff about ongoing concerns at ICU discharge.

<sup>b</sup> Prepare a discharge letter to the primary health practitioner if patients require ongoing need for support.

<sup>c</sup> People with persistent symptoms post COVID-19 should be reviewed, either in person or via telehealth. Communicate with primary care practitioner regarding rehabilitation needs and ongoing support.

Table by Thomas et al (2022). Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger, C. L., Hodgson, C., Holland, A. E., Jones, A. Y., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). [Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice recommendations](#). *Journal of Physiotherapy*, 68(1), 8–25. <https://doi.org/10.1016/j.jphys.2021.12.012>. © 2022 by the authors. This is an open-access article distributed in accordance with the Creative Commons Attribution Non Commercial No Derivatives (CC BY-NC-ND 4.0) license, which permits others to share this work non-commercially without derivatives, provided the original work is properly cited and appropriate credit is given. See:

<http://creativecommons.org/licenses/by-nc-nd/4.0/>

It has been suggested that physiotherapists should screen patients at various time points across the continuum of care (whether they were initially managed in hospital or the community)<sup>51</sup> so that patients with Long COVID may be identified early and referred for appropriate and timely follow-up.

## General assessment

General assessment may include the following:



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*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-34>

51. Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger C. L., Hodgson, C., Holland, A. E., Jones, A. Y.M., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice recommendations. *Journal of Physiotherapy*, 68, 8-25. <https://doi.org/10.1016/j.jphys.2021.12.012>



## Important - Desaturation

A drop in pulse oximetry saturation of greater than 3-4% from baseline measurement or to 94% or below during exercise testing is considered **desaturation**<sup>5253</sup> and may warrant further investigation. This will be determined by the physiotherapist on a case-by-case basis.

There are few Long COVID specific outcome measures and the use of patient-reported outcome measures developed for other conditions may not be applicable or relevant when applied to those with Long COVID<sup>54</sup>. There is a clear need for Long COVID

52. Postigo-Martin P, Cantarero-Villanueva I, Lista-Paz A, Castro-Martín E, Arroyo-Morales M, Seco-Calvo J. A COVID-19 Rehabilitation Prospective Surveillance Model for Use by Physiotherapists. *Journal of Clinical Medicine*. 2021; 10(8):1691. <https://doi.org/10.3390/jcm10081691>
53. World Health Organization. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
54. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

specific tools to be developed and tested. The following tools are currently being used in Long COVID research or within Australian Long COVID clinics.

### *General screening tools*

[COVID-19 Yorkshire Rehabilitation Scale](#) (C19-YRS)

[WHO Post COVID-19 Case Report Form](#) (CRF)

[Post-COVID-19 Functional Status Assessment](#) (PCFS)

### *Cardiorespiratory screening tools*

[Modified Medical Research Council \(mMRC\) Dyspnoea Scale](#)  
[\(Brompton\) Breathing Pattern Assessment Tool \(BPAT\)](#)

[Nijmegen questionnaire](#)

### *Functional and exercise capacity tests*

It is important to note, when considering functional or exercise capacity tests, that physical exertion may significantly exacerbate symptoms in some people experiencing Long COVID. Clinical judgement should be used as these tests may not be suitable for all but may offer a useful baseline measure<sup>55</sup>.

55. National Institute for Health and Care Excellence (NICE), Royal College of General Practitioners (RCGP) & Scottish Intercollegiate Guidelines Network (SIGN). (2022). COVID-19 rapid guideline: managing the long-term effects of COVID-19 (NICE guideline NG188). Retrieved April 18, 2023 from <https://www.nice.org.uk/guidance/ng188>

[1-minute Sit-To-Stand Test \(1STST\)](#)  
[2-Minute Walk Test \(2MWT\)](#)  
[Timed Up and Go Test \(TUG\)](#)  
[10-Meter Walk Test \(10MWT\)](#)  
[6-Minute Walk Test \(6MWT\)](#)  
[Cardiopulmonary Exercise Test \(CPET\)](#)  
[Tinetti Gait and Balance Assessment Tool](#)

## *Quality of life*

[EuroQOL EQ-5D-5L](#)  
[WHODAS 2.0](#)

## *Psychosocial*

[Generalised Anxiety Disorder-7 \(GAD-7\)](#)  
Depression Anxiety and Stress Scale (DASS-21)  
Hospital Anxiety and Depression Scale (HADS)

## *Other*

[Fatigue Severity Scale \(FSS\)](#)  
[DePaul Post-Exertional Malaise Questionnaire](#)  
Fatigue Scale for Motor and Cognitive Functions  
Functional Assessment of Chronic Illness Therapy – Fatigue Scale (FACIT-F)  
Brief Questionnaire to Screen for Post-Exertional Symptom Exacerbation (PESE)

## *Putting it all together*

A proposed surveillance model for use by physiotherapists is

presented in the figure below and includes three distinct and scaffolded sections to ensure a comprehensive assessment: a rapid screening, a general assessment and specific assessments that recommend various tools and parameters to aid treatment and management planning<sup>56</sup>. Rapid screening is designed to initially exclude new acute infection with **SARS-CoV-2**, noting that people experiencing Long COVID may otherwise answer yes to this question as they may be experiencing symptoms attributable to COVID-19, but this will not necessarily require onwards referral. It is important that the line of questioning within this section also details the patient's symptoms and how these symptoms behave over time. Most importantly, there must be a clear discussion around the goals of physiotherapy treatment. In regard to general assessment in an outpatient setting, auscultation is unlikely to provide any additional information to the patient's overall picture and thus is generally not necessary to perform. Finally, referral to a pulmonary rehabilitation program is typically based on symptoms and functional limitations rather than solely based on impaired spirometry findings. The suggested treatments shown in the grey shaded boxes are just that - suggestions.

56. Postigo-Martin P, Cantarero-Villanueva I, Lista-Paz A, Castro-Martín E, Arroyo-Morales M, Seco-Calvo J. A COVID-19 Rehabilitation Prospective Surveillance Model for Use by Physiotherapists. *Journal of Clinical Medicine*. 2021; 10(8):1691. <https://doi.org/10.3390/jcm10081691>

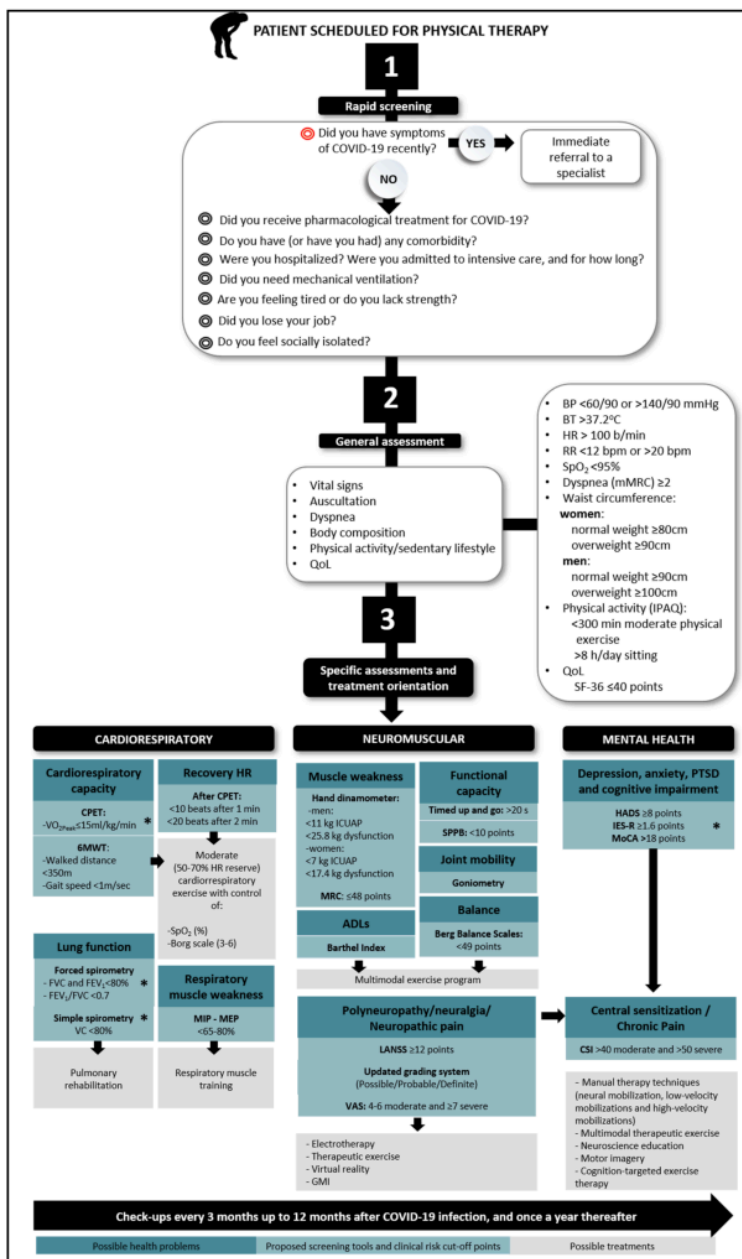


Figure by Postigo-Martin et al (2021). Postigo-Martin, P.,

Cantarero-Villanueva, I., Lista-Paz, A., Castro-Martín, E., Arroyo-Morales, M., Seco-Calvo, J. (2021). [A COVID-19 Rehabilitation Prospective Surveillance Model for Use by Physiotherapists](https://doi.org/10.3390/jcm10081691). *Journal of Clinical Medicine*. 2021; 10(8):1691. <https://doi.org/10.3390/jcm10081691> © 2021 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license. See <https://creativecommons.org/licenses/by/4.0/>.

## Learning activity (20 mins)



An interactive H5P element has been excluded from this version of the text. You can view it online here:

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-44>

Considering the persona of [Jarrod](#), outline your assessment plan.

Which screening tools might you use for Jarrod and why?

# Exercise-based rehabilitation for Long COVID

Physiotherapy and exercise-based rehabilitation are traditionally considered fundamental to recovery following illness<sup>57</sup>. However, the evidence to guide best practice physiotherapy management in people experiencing Long COVID remains unclear<sup>58,59,60</sup>.

57. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
58. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
59. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022). Practicalities for Exercise Prescription in Long-COVID-19 Rehabilitation. A Narrative Review. *Medical Research Archives*, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>
60. Dillen, H., Bekkering, G., Gijssbers, S., Weygaerde, Y.V., Van Herck, M., Haesevoets, S., Bos, D.A.G., Li, A., Janssens, W., Gosselink, R., Troosters, T., and Verbakel, J.Y. (2023). Clinical effectiveness of rehabilitation in ambulatory care for patients with persisting symptoms after COVID-19: a systematic review.

Physiotherapists, with their known expertise in movement, function, and rehabilitation<sup>61</sup>, play a vital role in helping individuals regain physical function, alleviate symptoms, and improve their overall quality of life<sup>62</sup>. People experiencing Long COVID who have a reduced physical capacity and associated symptoms should be considered for referral to exercise-based rehabilitation<sup>63</sup>.

Exercise-based rehabilitation for Long COVID should encompass a tailored program of **physical activity** that addresses the unique needs and limitations of each

BMC Infectious Diseases, 23, 419. <https://doi.org/10.1186/s12879-023-08374-x>

61. Allied Health Professions Australia. (2023) Physiotherapy. Retrieved July 14, 2023, from <https://ahpa.com.au/allied-health-professions/physiotherapy/>
62. Australian Physiotherapy Association. (2023) What Is Physio? Retrieved March 21, 2023, from <https://choose.physio/what-is-physio>
63. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022). Practicalities for Exercise Prescription in Long-COVID- 19 Rehabilitation. A Narrative Review. Medical Research Archives, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>



individual<sup>64656667</sup>. Rehabilitation programs may include a combination of education<sup>68</sup> (including pacing, pain

64. DeMars, J., Brown, D.A., Angelidis, I., Jones, F., McGuire, F., O'Brien, K.K., Oller, D., Pemberton, S., Tarrant, R., Verduzco-Gutierrez, M., & Gross, D.P. (2022). What is Safe Long COVID Rehabilitation? *Journal of Occupational Rehabilitation* 33, 227–230 (2023). <https://doi.org/10.1007/s10926-022-10075-2>
65. Nopp, S., Moik, F., Klok, F.A., Gattinger, D., Petrovic, M., Vonbank, K., Koczulla, A.R., Ay, C., & Zwick, R.H. (2022). Outpatient Pulmonary Rehabilitation in Patients with Long COVID Improves Exercise Capacity, Functional Status, Dyspnea, Fatigue, and Quality of Life. *Respiration*, 101 (6), 593-601. <https://doi.org/10.1159/000522118>
66. Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger C. L., Hodgson, C., Holland, A. E., Jones, A. Y.M., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice recommendations. *Journal of Physiotherapy*, 68, 8-25. <https://doi.org/10.1016/j.jphys.2021.12.012>
67. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
68. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

management, self-management among others), aerobic and resistance training<sup>69707172</sup>.

Physiotherapists play an important role in ensuring the safety and effectiveness of the **exercise** program, as well as making appropriate modifications based on the individual symptomatology and progress of the patient<sup>73</sup>.

69. Barbara, C., Clavario, P., De Marzo, V., Lotti, R., Guglielmi, G., Porcile, A., Russo, C., Griffo, R., Mäkilä, T., Hautala, A.J., & Porto, I., (2022). Effects of exercise rehabilitation in patients with long coronavirus disease 2019. *European Journal of Preventive Cardiology*, 29, e258-e260. <https://doi.org/10.1093/eurjpc/zwac019>
70. Nopp, S., Moik, F., Klok, F.A., Gattinger, D., Petrovic, M., Vonbank, K., Koczulla, A.R., Ay, C., & Zwick, R.H. (2022). Outpatient Pulmonary Rehabilitation in Patients with Long COVID Improves Exercise Capacity, Functional Status, Dyspnea, Fatigue, and Quality of Life. *Respiration*, 101 (6), 593-601. <https://doi.org/10.1159/000522118>
71. Smith, J.L., Deighton, K., Innes, A.Q., Holl, M., Mould, L., Liao, Z., Doherty, P., Whyte, G., King, J.A., Deniszczyc, D. & Kelly, B.M. (2023). Improved clinical outcomes in response to a 12-week blended digital and community-based long-COVID-19 rehabilitation programme. *Front. Med.* 10:1149922. <https://doi.org/10.3389/fmed.2023.1149922>
72. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022). Practicalities for Exercise Prescription in Long-COVID-19 Rehabilitation. A Narrative Review. *Medical Research Archives*, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>
73. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from <https://world.physio/sites/default/files/2021-07/Briefing->

## *Precautions and contraindications to exercise; an overview*

Precautions and contraindications to exercise-based rehabilitation in Long COVID should be considered to ensure the safety and well-being of individuals. While exercise is considered to be generally beneficial, people living with Long COVID may experience symptom exacerbation (i.e., if [Post Exertional Symptom Exacerbation](#) or PESE is present) or reduction in their current levels of participation if the unique characteristics of Long COVID are not considered<sup>74</sup>.

### Important - RED flags for rehabilitation

As per the [WHO guidelines](#)<sup>75</sup>, assessment, further

[Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](#)

- 74. DeMars, J., Brown, D.A., Angelidis, I., Jones, F., McGuire, F., O'Brien, K.K., Oller, D., Pemberton, S., Tarrant, R., Verduzco-Gutierrez, M., & Gross, D.P. (2022). What is Safe Long COVID Rehabilitation? *Journal of Occupational Rehabilitation* 33, 227–230 (2023). <https://doi.org/10.1007/s10926-022-10075-2>
- 75. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

investigation and management of patients with complications related to their COVID-19 acute infection, including significant cardiac impairment (which may present as: chest pain, palpitations or an altered resting heart rate  $>100\text{bpm}$ <sup>76</sup>), or respiratory desaturation below recommended parameters ( $<94\%$ ), is strongly recommended prior to the commencement of a rehabilitation program to rule out potentially life-threatening complications.

Whilst there is not a set list of tests or investigations for red flags, thorough assessment and an understanding of the person experiencing Long COVID symptoms and their patterns will assist in minimising risk when commencing exercise-based rehabilitation.

## *Contraindications*

There are no specific contraindications to commencing supervised exercise-based rehabilitation for people experiencing Long COVID provided any reported/observed red flags for safe exercise have been investigated and addressed<sup>77</sup>.

76. Postigo-Martin P, Cantarero-Villanueva I, Lista-Paz A, Castro-Martín E, Arroyo-Morales M, Seco-Calvo J. A COVID-19 Rehabilitation Prospective Surveillance Model for Use by Physiotherapists. *Journal of Clinical Medicine*. 2021; 10(8):1691. <https://doi.org/10.3390/jcm10081691>

77. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022).

## *Precautions*

### *Symptom monitoring*

People with Long COVID may experience fluctuating symptoms resembling those found in other post-viral syndromes such as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (**ME/CFS**)<sup>79</sup>.

Symptoms and response to exercise should be monitored closely during, immediately after and in the days following exercise therapy<sup>80,81</sup>. A symptom or activity diary may be a

Practicalities for Exercise Prescription in Long-COVID- 19 Rehabilitation. A Narrative Review. Medical Research Archives, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>

78. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
79. DeMars, J., Brown, D.A., Angelidis, I., Jones, F., McGuire, F., O'Brien, K.K., Oller, D., Pemberton, S., Tarrant, R., Verduzco-Gutierrez, M., & Gross, D.P. (2022). What is Safe Long COVID Rehabilitation? Journal of Occupational Rehabilitation 33, 227–230 (2023). <https://doi.org/10.1007/s10926-022-10075-2>
80. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
81. DeMars, J., Brown, D.A., Angelidis, I., Jones, F., McGuire, F., O'Brien, K.K., Oller, D., Pemberton, S., Tarrant, R., Verduzco-Gutierrez, M., & Gross, D.P. (2022). What is Safe Long COVID Rehabilitation? Journal of Occupational Rehabilitation 33, 227–230 (2023). <https://doi.org/10.1007/s10926-022-10075-2>

useful tool to assist in this process - click [here](#) for a downloadable diary template.

If, despite the use of pacing/gradual progression/loading, the exercise consistently exacerbates symptoms and results in prolonged worsening of overall health and wellbeing, it may be necessary to reassess the exercise program and consider alternative approaches.

### *Exertional oxygen desaturation and breathlessness*

Physical activity increases oxygen demand, and when significant exertional oxygen **desaturation** is present, commencing exercise-based rehabilitation should be undertaken with caution. Whilst rare, some patients may develop long-term cardiac and pulmonary complications after an acute COVID-19 infection<sup>82</sup> which may inhibit their ability to participate in exercise. Referral to a Pulmonary Rehabilitation program and/or a Respiratory Physiotherapist should be considered for patients presenting with symptoms of Post-COVID lung disease as, in these cases, it may not be possible to prevent exertional desaturation.

**Symptom titrated physical activity**<sup>83</sup> may be considered within a rehabilitation program where exertional oxygen desaturation is present<sup>84</sup>.

82. Postigo-Martin P, Cantarero-Villanueva I, Lista-Paz A, Castro-Martín E, Arroyo-Morales M, Seco-Calvo J. A COVID-19 Rehabilitation Prospective Surveillance Model for Use by Physiotherapists. *Journal of Clinical Medicine*. 2021; 10(8):1691. <https://doi.org/10.3390/jcm10081691>

83. NIHR Themed Review: Living with Covid19 - Second review; March 2021; doi:10.3310/themedreview\_45225

84. World Physiotherapy. (2021). World Physiotherapy Response to

Breathing Pattern Disorders (BPD) including **hyperventilation syndrome** may be present for some people experiencing Long COVID even if no exertional desaturation is present<sup>85</sup>. Additionally, many patients may experience breathlessness without desaturation and no evidence of breathing pattern disorders. Breathlessness may result due to prolonged reduced participation and resultant deconditioning. Exercise-based rehabilitation aims to teach people experiencing breathlessness that these sensations are normal, and to give them tools and strategies to assist in self-management.

During exercise rehabilitation sessions, oxygen saturation and **dyspnoea** symptoms should be monitored throughout using established criteria and outcome measures<sup>8687</sup>.

COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

85. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
86. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022). Practicalities for Exercise Prescription in Long-COVID- 19 Rehabilitation. A Narrative Review. Medical Research Archives, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>
87. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for

## Important - When to reduce exercise intensity

The criteria for reduction in intensity and/or ceasing exercise<sup>8889</sup>:

- A drop in **SpO<sub>2</sub>** of > 3-4% from baseline measurement<sup>90</sup>

people living with Long COVID: physical activity and exercise.

London, UK: World Physiotherapy; 2021. Available from

[https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

88. Kortianou E.A., Mavronasou A., & Sapouna, V. (2022).

Practicalities for Exercise Prescription in Long-COVID- 19 Rehabilitation. A Narrative Review. Medical Research Archives, 10(5), June 2022. <https://doi.org/10.18103/mra.v10i5.2801>

89. World Physiotherapy. (2021). World Physiotherapy Response to

COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise.

London, UK: World Physiotherapy; 2021. Available from

[https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

90. World Health Organisation. (2023, August 18). Clinical

management of COVID-19: living guideline.



- **SpO<sub>2</sub> < 90%**
- **Modified Borg Dyspnoea Scale ≥ 6**
- Shortness of breath with no relief after rest
- Chest pain or tightness
- Dizziness
- Headache
- Blurred vision
- **Palpitation**
- **Tachycardia**
- **Syncope**

### *Heart rate and exercise*

Cardiac impairment following COVID-19 infection has been

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

well documented in the literature<sup>91929394</sup>. Exercise restrictions are recommended in the presence of acute cardiac conditions (e.g., acute **myocarditis**) because exercise can increase the risk of mortality and morbidity<sup>95</sup>.

91. Kotecha, T., Knight, D. S., Razvi, Y., Kumar, K., Vimallesvaran, K., Thornton, G., Patel, R., Chacko, L., Brown, J. T., Coyle, C., Leith, D., Shetye, A., Ariff, B., Bell, R., Captur, G., Coleman, M., Goldring, J., Gopalan, D., Heightman, M., Hillman, T., ... Fontana, M. (2021). Patterns of myocardial injury in recovered troponin-positive COVID-19 patients assessed by cardiovascular magnetic resonance. *European heart journal*, 42(19), 1866–1878.  
<https://doi.org/10.1093/eurheartj/ehab075>
92. Yan Z, Yang M, Lai C-L. Long COVID-19 Syndrome: A Comprehensive Review of Its Effect on Various Organ Systems and Recommendation on Rehabilitation Plans. *Biomedicines*. 2021; 9(8):966. <https://doi.org/10.3390/biomedicines9080966>
93. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
94. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
95. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from <https://world.physio/sites/default/files/2021-07/Briefing->

There is a potential for the delayed development of cardiac dysfunction in people experiencing Long COVID<sup>96</sup>. Any changes to cardiac signs and symptoms during or after exercise warrants further clinical assessment and/or investigation<sup>9798</sup>.

## Important - Signs / symptoms of

[Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](#)

96. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
97. Thomas, P., Baldwin, C., Beach, L., Bissett, B., Boden, I., Cruz, S. M., Gosselink, R., Granger C. L., Hodgson, C., Holland, A. E., Jones, A. Y.M., Kho, M. E., van der Lee, L., Moses, R., Ntoumenopoulos, G., Parry, S. M., & Patman, S. (2022). Physiotherapy management for COVID-19 in the acute hospital setting and beyond: an update to clinical practice recommendations. *Journal of Physiotherapy*, 68, 8-25.  
<https://doi.org/10.1016/j.jphys.2021.12.012>
98. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from  
[https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

## suspected cardiac impairment<sup>99100</sup>

- Chest pain
- Difficulty breathing
- High resting or exertional heart rate
- Increased respiratory rate
- Reduced oxygen saturation
- Palpitations
- Reduced exercise tolerance

There is currently no consensus on recommended heart rate parameters for exercise-based rehabilitation in patients living with Long COVID.

99. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
100. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from  
[https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

## Key message

It is important for individuals experiencing Long COVID to work closely with their healthcare team, to determine appropriate exercise guidelines and make necessary adjustments based on their individual circumstances and symptomatology.

Exercise-based rehabilitation should be a slow and careful process respecting patient symptoms and response to the exercise program.

## *Post-Exertional Symptom Exacerbation (PESE)*



One or more interactive elements has been excluded from this version of the text. You can view them online here: <https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#oembed-1>

**PESE** is a phenomenon characterized by the triggering or worsening of symptoms following minimal physical, emotional,

social or cognitive exertion<sup>101102</sup>. Symptoms may worsen 12 to 72 hours following activity and may last for days or weeks<sup>103104</sup>. The severity and duration of PESE can vary widely among individuals. PESE has been associated with other disabling conditions such as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (**ME/CFS**)<sup>105</sup>. One international study that

101. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
102. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
103. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
104. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
105. Twomey, R., DeMars, J., Franklin, K., Culos-Reed, S. N., Weatherald, J., & Wrightson, J. G. (2022). Chronic Fatigue and Postexertional Malaise in People Living With Long COVID: An Observational Study. *Physical therapy*, 102(4), pzac005.  
<https://doi.org/10.1093/ptj/pzac005>

surveyed people seven months after a suspected or confirmed COVID-19 infection, found that 89.1% of the respondents reported either physical or mental post-exertional fatigue malaise<sup>106</sup>.

PESE can manifest as increased fatigue, exercise intolerance, pain, cognitive dysfunction or 'brain fog', sleep disturbances or general malaise<sup>107</sup>. Patients with

**"If I don't get this right, I will crash as soon as I get back to work..."**  
**(Jarrod, 42year old)**

PESE may report a reduced capacity to work or study, alongside negative effects on physical functioning, exercise tolerance and social activity<sup>108</sup>. Patients may often describe

106. Davis, H.E., Assaf, G.S., McCorkell, L., Wei, H., Low, R.J., Re'em, Y., Redfield, S., Austin, J.P., & Akrami, A. (2021). Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*, 38 (101019). <https://doi.org/10.1016/j.eclinm.2021.101019>

107. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

108. Twomey, R., DeMars, J., Franklin, K., Culos-Reed, S. N., Weatherald, J., & Wrightson, J. G. (2022). Chronic Fatigue and Postexertional Malaise in People Living With Long COVID: An Observational Study. *Physical therapy*, 102(4), pzac005. <https://doi.org/10.1093/ptj/pzac005>

experiencing a 'crash' after activity if symptom exacerbation is experienced over a longer timeframe<sup>109</sup>.

Symptom stabilisation should be the initial aim<sup>110111</sup>.

## Important - Graded exercise

**Graded exercise** approaches and fixed activity prescription should not be used in patients

109. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
110. Twomey, R., DeMars, J., Franklin, K., Culos-Reed, S. N., Weatherald, J., & Wrightson, J. G. (2022). Chronic Fatigue and Postexertional Malaise in People Living With Long COVID: An Observational Study. *Physical therapy*, 102(4), pzac005. <https://doi.org/10.1093/ptj/pzac005>
111. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>



experiencing PESE<sup>112113</sup>. Activity and exercise prescription should instead be titrated to the individual's symptoms. The “Stop. Rest. Pace” activity management message along with heart rate monitoring may assist patients with PESE to self-manage with the support of their healthcare provider/s<sup>114</sup>.

### *Pacing and activity management*

**Pacing** involves employing a range of strategies to avoid both

- 112. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
- 113. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>
- 114. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)

over- and under-exertion, rather than being a form of avoidance behaviour<sup>115116</sup>. Evidence for the use of pacing and activity modification as a self-management strategy in people experiencing Long COVID and PESE is limited<sup>117118</sup>.

115. Décary, S., Gaboury, I., Poirier, S., Garcia, C., Simpson, S., Bull, M., Brown, D., & Daigle, F. (2021)[Editorial]. Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Journal of Orthopaedic & Sports Physical Therapy*, 51 (5); 197-200.  
<https://doi.org/10.2519/jospt.2021.0106>
116. Ghali, A., Lacombe, V., Ravaiau, C., Delattre, E., Ghali, M., Urbanski, G., & Lavigne, C. (2023). The relevance of pacing strategies in managing symptoms of post-COVID-19 syndrome. *Journal of Translational Medicine*, 21 (375).  
<https://doi.org/10.1186/s12967-023-04229-w>
117. Décary, S., Gaboury, I., Poirier, S., Garcia, C., Simpson, S., Bull, M., Brown, D., & Daigle, F. (2021)[Editorial]. Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Journal of Orthopaedic & Sports Physical Therapy*, 51 (5); 197-200.  
<https://doi.org/10.2519/jospt.2021.0106>
118. Ghali, A., Lacombe, V., Ravaiau, C., Delattre, E., Ghali, M., Urbanski, G., & Lavigne, C. (2023). The relevance of pacing strategies in managing symptoms of post-COVID-19 syndrome. *Journal of Translational Medicine*, 21 (375).  
<https://doi.org/10.1186/s12967-023-04229-w>

## Important - Pacing theories

### ***The spoon theory***

The Spoon Theory illustrates the limited energy reserves individuals with chronic conditions possess by using spoons as a metaphorical representation of units of energy. Each activity throughout the day "costs" a certain number of spoons, depleting the available energy pool. Once spoons have been used, the person is more likely to experience fatigue or symptom exacerbation. Managing daily tasks becomes a matter of rationing and carefully prioritising spoon expenditure to prevent overexertion and maintain the ability to participate in activities. This theory was developed by people with chronic disease and disability as a way of describing their experience.

For further information, visit '[The Spoon Theory](#)' written by Christine Miserandino. Christine lives with lupus, and the theory is based on her lived experience of managing this condition.

## ***The energy envelope theory***<sup>119</sup>

This theory proposes that individuals with limited energy resources can manage their well-being by recognising their perceived energy limits. By pacing activities, avoiding overexertion, and balancing rest, they aim to stay within their 'energy envelope'. This in turn aims to minimise symptoms and enhance overall functioning.

For further information, visit '[Finding your Envelope](#)' by Bruce Campbell

Pacing strategies may include<sup>120121</sup>:

119. Jason, Leonard A., Melrose, Harriet, Lerman, Allison, Burroughs, Veronica, Lewis, Kelly, King, Caroline P., & Frankenberry, Erin L. (1999). Managing Chronic Fatigue Syndrome: Overview and Case Study. AAOHN Journal, 47(1), 17–21. <https://doi.org/10.1177/216507999904700104>
120. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
121. Ghali, A., Lacombe, V., Ravaiau, C., Delattre, E., Ghali, M., Urbanski, G., & Lavigne, C. (2023). The relevance of pacing strategies in managing symptoms of post-COVID-19



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here:

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-39>

## Heart Rate (HR) monitoring

In **ME/CFS HR** during exercise is encouraged to be kept within the 'energy envelope' (i.e., below the anaerobic threshold), as breaching this threshold may trigger **PESE**<sup>122</sup>. This may be relevant for those individuals with Long COVID and PESE. HR monitoring can be used to guide working within one's 'energy envelope', thus ensuring that overall energy expenditure is less likely to result in PESE.

Useful guides to calculate appropriate resting HR and HR that indicates the anaerobic threshold can be found here;

syndrome. Journal of Translational Medicine, 21 (375).

<https://doi.org/10.1186/s12967-023-04229-w>

122. Campbell, B. (2021, October 4). Pacing by Numbers: Using your heart rate to stay inside the energy envelope. ME/CFS & Fibromyalgia Self-Help. <https://www.cfselfhelp.org/library/pacing-numbers-using-your-heart-rate-to-stay-inside-energy-envelope>

Emerge Australia

[Pacing with a heart rate monitor \(Factsheet\)](#)

Workwell Foundation

[Heart Rate Monitor \(Factsheet\)](#)

Physio For Me

[Heart Rate Monitoring \(Website\)](#)

### *Education and supported self-management*

Education regarding self-management strategies is important for patients experiencing PESE<sup>123</sup>. Physiotherapists should support self-care strategies and adaptive coping mechanisms by providing information and resources about PESE. This is an important part of the management as appropriate education empowers individuals to self-monitor and make informed decisions about their ongoing care, health and well-being.

### *Autonomic dysfunction*

Autonomic dysfunction, also known as Autonomic Nervous System (**ANS**) dysfunction or dysautonomia, refers to disruption or impairment in the normal functioning of the

123. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.  
<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

ANS<sup>124</sup>. The ANS is responsible for regulating and controlling involuntary bodily functions, such as heart rate, blood pressure, gastrointestinal motility, respiratory rate and temperature regulation<sup>125126127</sup>. It consists of two main branches: the

124. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>
125. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
126. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>
127. Espinosa-Gonzalez A B, Master H, Gall N, Halpin S, Rogers N, Greenhalgh T et al. Orthostatic tachycardia after covid-19 *BMJ* 2023; 380 :e073488 <https://doi.org/10.1136/bmj-2022-073488>

sympathetic nervous system and the parasympathetic nervous system.

When autonomic dysfunction occurs, it can disrupt the balance between these two branches, leading to a range of symptoms and issues. Due to the ANS role in regulating blood flow and therefore oxygen delivery to muscles, individuals with autonomic dysfunction might experience fatigue and exercise intolerance, along with other symptoms such as breathlessness, chest pain, palpitations and **presyncope**<sup>128</sup>.

Autonomic dysfunction encapsulates a broader spectrum of dysregulation within the ANS, affecting various physiological functions<sup>129</sup>.

128. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)
129. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). PM&R. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>



## Key message - Autonomic dysfunction

If you suspect either yourself or someone you know is experiencing autonomic dysfunction, it's important to consult a medical professional for an accurate diagnosis and management plan.

### *Orthostatic intolerance*

Orthostatic intolerance occurs due to an abnormal autonomic response to postural change<sup>130</sup>. Patients can present with either resting or postural hypotension and/or tachycardia<sup>131,132</sup>.

130. Dani M, Dirksen A, Taraborrelli P, Torocastro M, Panagopoulos D, Sutton R, Lim PB. Autonomic dysfunction in 'long COVID': rationale, physiology and management strategies. Clin Med (Lond). 2021 Jan;21(1):e63-e67. <https://doi.org/10.7861/clinmed.2020-0896>
131. Dani M, Dirksen A, Taraborrelli P, Torocastro M, Panagopoulos D, Sutton R, Lim PB. Autonomic dysfunction in 'long COVID': rationale, physiology and management strategies. Clin Med (Lond). 2021 Jan;21(1):e63-e67. <https://doi.org/10.7861/clinmed.2020-0896>
132. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-

The term orthostatic intolerance may be used when objective tests have been unable to confirm a diagnosis of the common autonomic disorders<sup>133</sup>.

### *Postural Orthostatic Tachycardia Syndrome (POTS)*

**POTS** is considered a disorder of the **ANS** that is associated with **tachycardia** upon standing<sup>134</sup>.

Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>

133. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>
134. Espinosa-Gonzalez A., Master H., Gall N., Halpin S., Rogers N., & Greenhalgh T. (2023). Orthostatic tachycardia after covid-19. *BMJ*; 380 :e073488 <https://doi.org/10.1136/bmj-2022-073488>

It is clinically defined as<sup>135136</sup>:

- a **HR** increase of  $\geq 30$  bpm within 10 minutes of standing up without significant hypotension or
- HR  $>120$  bpm for 10 minutes on standing without significant hypotension

### *Self-management and exercise*

Whilst limited evidence exists to manage autonomic dysfunction for people living with Long COVID, education and exercise have been recommended as part of the management<sup>137138</sup>.

135. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>
136. Espinosa-Gonzalez A., Master H., Gall N., Halpin S., Rogers N., & Greenhalgh T. (2023). Orthostatic tachycardia after covid-19. *BMJ*; 380 :e073488 <https://doi.org/10.1136/bmj-2022-073488>
137. Dani M, Dirksen A, Taraborrelli P, Torocastro M, Panagopoulos D, Sutton R, Lim PB. Autonomic dysfunction in 'long COVID': rationale, physiology and management strategies. *Clin Med (Lond)*. 2021 Jan;21(1):e63-e67.<https://doi.org/10.7861/clinmed.2020-0896>
138. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.

Education should include identification of symptom aggravating and easing factors, as well as including instruction on counterpressure maneuvers such as crossing the legs while standing<sup>139</sup>. Other education for self-management includes (but is not limited to):<sup>140</sup>



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-42>

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

139. Blitshteyn S., Whiteson, J.H., Abramoff, B., Azola, A., Bartels, M.N., Bhavaraju-Sanka, R., Chung, T., Fleming, T.K., Henning, E., Miglis, M.G., Sampsel, S., Silver, J.K., Tosto, J., Verduzco-Gutierrez, M., & Putrino, D. (2022). Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). *PM&R*. 2022;14(10):1270-1291. <https://doi.org/10.1002/pmrj.12894>
140. Kavi, L. (2022). Postural tachycardia syndrome and long COVID: an update. *British Journal of General Practice*, 72, (714), 8-9. <https://doi.org/10.3399/bjgp22X718037>

## *Autonomic Conditioning Therapy (ACT)*

Autonomic conditioning therapy or **ACT** is one rehabilitation protocol that has been shown to improve fatigue in people experiencing Long COVID<sup>141</sup>.

ACT involves participation in a supervised, gradual, symptom-oriented exercise program consisting of three phases of rehabilitation<sup>142</sup>:

141. Putrino, D., Tabacof, L., Tosto-Mancuso, J., Wood, J., Cortes, M., Kontorovich, A., McCarthy, D., Breyman, E., Nasr, A., Duntz, J., Bunt, A., Herrera, J., & Kellner, C. (2021). Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. Research Square. <https://doi.org/10.21203/rs.3.rs-440909/v1>
142. Putrino, D., Tabacof, L., Tosto-Mancuso, J., Wood, J., Cortes, M., Kontorovich, A., McCarthy, D., Breyman, E., Nasr, A., Duntz, J., Bunt, A., Herrera, J., & Kellner, C. (2021). Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. Research Square. <https://doi.org/10.21203/rs.3.rs-440909/v1>

## Autonomic Conditioning Therapy Program<sup>143</sup>

### PHASE 1

**Phase 1A:** Supine active **ROM** exercises (over minimum of 2 weeks)

- **AROM** knee flexion heel slides
- AROM hip abduction

- **SLR**

- Hip bridging

Performed bilaterally over 30second intervals at an **RPE** 2/10 on modified Borg scale

Recovery breathing (4 sec inhale / 6 sec exhale) between sets

**Phase 1B:** Upright exercise

- Seated hip adduction ball squeeze
  - Seated **AROM** hip flexion marches
  - Seated concentric quadriceps long arc
  - Side-lying hip abduction clamshells
  - Modified (high kneeling) plank
  - Continue **SLR** and bridging exercise from phase 1A
- 2x sets of 10 reps each exercise, plank 2x 10sec holds

### PHASE 2

**Phase 2A:** Progressive submaximal aerobic exercises (over 4 weeks)

- overground walking intervals

Week 1: 5x 1 minute intervals progressing to Week 4: 5x 90second intervals

Goal to complete total of 6 minutes aerobic training time

**Phase 2B:** Continue progression of submaximal aerobic training (over 4 weeks)

Week 1: 3x 2minute intervals progressing to Week 4: 6x 2minute intervals

Goal of phase 2B to complete total 12 minutes aerobic training

### PHASE 3

**Phase 3/ Levine protocol:** Progressive and graded aerobic exercise program (over 6 weeks)

- 3x sessions / week

- Approximately 25-30minutes recumbent bike per session initially

- Protocol based on training zones

Base pace = 75% age predicted maximum HR and **RPE** of 13-16

Maximum steady state = RPE 16-18

Recovery pace = RPE 6-12

Importantly, patients participating in an ACT program should be progressively guided through the phases according to their individual symptom responses to the program<sup>144</sup>. Additionally, patients should be closely monitored for [PESE](#) throughout the rehabilitation program.

## Key messages

- Exercise-based rehabilitation for those experiencing Long COVID should:
  - be personalised
  - manage expectations
  - be psychologically supportive

Kontorovich, A., McCarthy, D., Breyman, E., Nasr, A., Duntz, J., Bunt, A., Herrera, J., & Kellner, C. (2021). Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. Research Square. <https://doi.org/10.21203/rs.3.rs-440909/v1>

144. Putrino, D., Tabacof, L., Tosto-Mancuso, J., Wood, J., Cortes, M., Kontorovich, A., McCarthy, D., Breyman, E., Nasr, A., Duntz, J., Bunt, A., Herrera, J., & Kellner, C. (2021). Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. Research Square. <https://doi.org/10.21203/rs.3.rs-440909/v1>

- avoid symptom exacerbation
- Exercise-based rehabilitation should focus on symptom stabilisation in the first instance, as well as strategies to sustain patient function without exacerbating symptoms<sup>145</sup>.
- Physiotherapists can guide the rehabilitation pathway of those experiencing Long COVID, by providing carefully designed programs tailored to the individual, that balance activity with adequate rest<sup>146</sup>.
- Consistent symptom monitoring is a vital component of exercise-based rehabilitation for patients experiencing Long COVID and should be incorporated before, during and after any exercise or physical activity.

145. DeMars, J., Brown, D.A., Angelidis, I., Jones, F., McGuire, F., O'Brien, K.K., Oller, D., Pemberton, S., Tarrant, R., Verduzco-Gutierrez, M., & Gross, D.P. (2022). What is Safe Long COVID Rehabilitation? *Journal of Occupational Rehabilitation* 33, 227–230 (2023). <https://doi.org/10.1007/s10926-022-10075-2>

146. World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021. Available from [https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged\\_in=true](https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf?logged_in=true)



## Learning activity (30 mins)

Read the persona of [Jarrod](#).

Jarrod's goals (in no particular order) are to:

- Return to work as a painter and decorator or in a related job.
- Feel less pain and stiffness in his body.
- Get back to completing all his activities for himself and no longer rely on others.
- Spend more time with his kids, including looking after them on his own.
- Get back into regularly riding, running and hiking to reconnect with nature.



**Jarrod Micallef.** Photo by [Tima Miroshnichenko](#) from [Pexels](#).

1. Considering Jarrod and his description of symptoms, what are the key safety concerns to consider when prescribing an exercise program for him?

Use the padlet to record your answers. **Remember that this is a public board, and please do not include any identifying information.** This padlet is best viewed in full-screen mode.



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-46>

Read the following open-access article - [Muscle abnormalities worsen after post-exertional malaise in long COVID](#) by Appelman et al.

2. Write an outline for an exercise program for Jarrod taking into account his goals, symptoms and the potential underlying pathophysiology of his condition. Include how you might modify exercises for him given his presenting symptoms, how exercise may be progressed according to his symptoms and what factors might indicate a need to cease the exercise-based rehabilitation program.

## Other physiotherapy treatment/s for Long COVID

In general terms, established symptom management approaches are recommended for people with Long COVID,

and as such, physiotherapists should consult existing clinical guidelines to guide their management<sup>147</sup>.

## Fatigue

Fatigue or exhaustion is commonly reported in those with Long COVID and may be a major barrier to **participation** to undertaking everyday tasks.

Pacing and energy conservation techniques may be useful tools for those with Long COVID, who experience fatigue.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=992#h5p-41>

**Symptom titrated physical activity** means engaging in physical activities, that may include exercise, only at a level guided by the presence and severity of symptoms, to mitigate exacerbating symptoms.

It is important to exclude the presence of **PESE** before commencing exercise-based rehabilitation<sup>148</sup>.

147. National COVID-19 Clinical Evidence Taskforce. (2023, May 30). Australian guidelines for the clinical care of people with COVID-19 (version 74.1). <https://app.magicapp.org/#/guideline/L4Q5An>

148. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.

For further information related to fatigue and its management please refer to the previous section on [PESE](#).

## *Pain management*

Patients with Long COVID may experience **arthralgia** which presents as inflammatory type pain in one or more joints, commonly the knees, ankles and/or wrists<sup>149</sup> as well as **myalgia**. Musculoskeletal pain as a symptom of Long COVID can be extremely debilitating and have a significant impact on function<sup>150</sup>.

There is currently no evidence supporting specific interventions to manage pain in patients with Long COVID. The WHO<sup>151</sup> recommends pain education, self-management strategies and physical exercise training (in the absence of **PESE**) to manage arthralgia, i.e., treatment should be as per standard practice.

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

149. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

150. Khoja, O., Passadouro, B.S., Mulvey, M., Delis, I., Astill, S., Tan, A.L., and Sivan, M. (2022). Clinical Characteristics and Mechanisms of Musculoskeletal Pain in Long COVID. Journal of Pain Research. 15:1729-1748 <https://doi.org/10.2147/JPR.S365026>

151. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline.

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

If chronic/persistent pain is present, or suspected to develop, referral to a Chronic Pain Clinic should be considered.

## *Breathing Pattern Disorders (BPD)*

Breathing Pattern Disorders (**BPD**), also known as breathing impairment or Dysfunctional Breathing (**DB**) can be defined as **dyspnoea** associated with an abnormal pattern of breathing in the absence of significant cardiopulmonary disease or dyspnoea that is out of proportion to an underlying cause<sup>152</sup>. **BPD** (including hyperventilation and dysfunctional breathing) are common in autonomic dysfunction and **POTS**.

BPD may be present at rest or during physical activity including activities of daily living and exercise<sup>153154</sup>. **Hyperventilation Syndrome** and Periodic Deep Sighing have

152. Genecand, L., Altarelli, M., Binkova, A., Loew, S., Vaudan, S., Gex, G., Bridevaux, P-O., & Frésard, I. (2023). Dysfunctional breathing symptoms, functional impact and quality of life in patients with long COVID-19: a prospective case series. *BMJ Open Respir Res.* 10:e001770. <https://doi.org/10.1136/bmjresp-2023-001770>
153. Genecand, L., Altarelli, M., Binkova, A., Loew, S., Vaudan, S., Gex, G., Bridevaux, P-O., & Frésard, I. (2023). Dysfunctional breathing symptoms, functional impact and quality of life in patients with long COVID-19: a prospective case series. *BMJ Open Respir Res.* 10:e001770. <https://doi.org/10.1136/bmjresp-2023-001770>
154. World Health Organisation. (2023, August 18). Clinical management of COVID-19: living guideline. <https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.2>

been described as the more common presentations of BPD in patients with Long COVID<sup>155</sup>.

The main physiotherapy intervention for patients experiencing BPD is breathing re-training, focusing on establishing a nose/diaphragm pattern of breathing and reducing overall ventilation.

Referral to a specialist respiratory physiotherapist should be considered, in order to optimise management of BPD.

### Learning activity (10 mins)

Read the persona of [Jarrod](#).

What additional physiotherapy treatment options (other than exercise) may be appropriate for Jarrod given his ongoing symptoms?

Are referrals to other health care providers required at this time for Jarrod?

155. Genecand, L., Altarelli, M., Binkova, A., Loew, S., Vaudan, S., Gex, G., Bridevaux, P-O., & Frésard, I. (2023). Dysfunctional breathing symptoms, functional impact and quality of life in patients with long COVID-19: a prospective case series. *BMJ Open Respir Res.* 10:e001770. <https://doi.org/10.1136/bmjresp-2023-001770>

## Self-management for Long COVID

It is recommended that self-management for Long COVID be incorporated into the recovery plan<sup>156</sup>.

Self-management for Long COVID is a broad topic that is currently not covered in detail in this chapter. Information to include or provide those with Long COVID include, but are not limited to:

- Physical activity and returning to exercise
- Management of more common presenting symptoms such as breathlessness or **persistent pain**
- Management of activities of daily living including general advice related to pacing and energy conservation
- Returning to work or study
- General advice related to nutrition and sleep hygiene
- Links to resources to support psychological wellbeing

The NHS [Your COVID Recovery website](#) is an example of best practice for supporting self-management of those presenting with milder impairments attributable to Long COVID<sup>157</sup>.

156. House of Representatives Standing Committee on Health, Aged Care and Sport (2023). Sick and tired: Casting a long shadow. Inquiry into Long COVID and Repeated COVID Infections. Parliament of Australia. Canberra. Available at: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc\\_pdf/SickandtiredCastingalongshadow.pdf](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc_pdf/SickandtiredCastingalongshadow.pdf)

157. House of Representatives Standing Committee on Health, Aged Care and Sport (2023). Sick and tired: Casting a long shadow. Inquiry into Long COVID and Repeated COVID Infections. Parliament of Australia. Canberra. Available at: <https://parlinfo.aph.gov.au/parlInfo/download/committees/>

# Conclusion

Physiotherapy plays an important role in optimising the recovery of patients with Long COVID. It is important that clinicians regularly reassess the patient's symptoms, their functional progress, and adherence to the recommended self-management strategies. Modification and adjustment of interventions may be required based on each individual's response to increasing their physical activity and/or exercise load.

It cannot be emphasised enough the importance of individualised management for patients with Long COVID. There is no "one-size fits all" approach to addressing the presenting impairments that may be observed in clinical practice. Working collaboratively with the wider multi-disciplinary healthcare team will result in optimal outcomes for each patient.

Whilst the information contained in this chapter is by no means exhaustive, it is designed to provide an overview and highlight key information for physiotherapists working with people diagnosed with Long COVID. Further reading and resources that may be beneficial for both patients and their families as well as health professionals are provided in the links below.

[reportrep/RB000006/toc\\_pdf/](#)  
[SickandtiredCastingalongshadow.pdf](#)



## Further information

The following links will provide you with additional information about Long COVID from credible sources. These listings are not exhaustive, and you are encouraged to seek out locally relevant information.

### **General resources for people with Long COVID and their families**

- Long COVID Physio - [Website](#)
- NHS - [Your COVID Recovery - I have or may have long COVID](#)
- Royal Australian College for General Practitioners (RACGP) - [Patient resource: Managing post-COVID-19 symptoms](#)
- Peer support groups  
[Long COVID Support Australia](#)  
[Lung Foundation Australia - COVID recovery support group](#)
- Provincial Health Services Authority (PHSA) - *Post-COVID-19 Interdisciplinary Clinical Care Network Resources* - [Living with Post-COVID symptoms \(website\)](#)
- Scottish Intercollegiate Guidelines Network (SIGN) - [Long COVID; A booklet for people who have signs and symptoms that continue or develop after acute COVID-19](#)
- World Health Organization (WHO) [Support for](#)

[rehabilitation: self-management after COVID-19-related illness](#)  
[Post-COVID-19 Condition](#) (factsheet)

### **Resources for specific symptoms of Long COVID**

- Breathing Pattern Disorders  
[Would you like to breathe better?](#)  
[Breathing dysfunction](#)
- Breathlessness  
[Asthma and Lung UK](#)
- Autonomic dysfunction  
[Dysautonomia International](#)
- Long COVID and **ME/CFS**  
[Long COVID and ME/CFS are they the same condition?](#)
- Post Exertional Symptom Exacerbation (PESE)  
Advice on energy and symptom management:  
[NICE guideline: Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#)  
[Activity and energy management - pacing](#)  
Emerge Australia Website: [Post-Exertional Malaise \(PEM\)](#)
- Postural Orthostatic Tachycardia Syndrome (POTS)  
[PoTS UK](#)

### **Health care professional resources**

- Australian Parliamentary Inquiry into Long COVID  
[Sick and tired: Casting a long shadow. Inquiry](#)

[into Long COVID and Repeated COVID Infections.](#)

- National Clinical Evidence Taskforce  
[Australian guidelines for the clinical care of people with COVID-19](#)  
[Care of people after COVID-19](#) (flowchart)
- National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN) and Royal College of General Practitioners (RCGP)[COVID-19 rapid guideline: managing the long-term effects of COVID-19](#)
- The Lancet  
[COVID-19 Resource Centre](#)
- Long COVID Physio  
[Resources](#)  
[Podcast episodes](#)
- Royal Australian College for General Practitioners (RACGP)  
[Caring for patients with pos-COVID-19 conditions](#)
- World Health Organization (WHO)  
[Clinical management of COVID-19: living guideline](#)  
[Post COVID-19 condition](#)

Please help us ensure this book chapter meets the needs of all readers by providing your feedback via the following satisfaction survey: [Brief Feedback](#)

[Survey – Improving the Participation Gap: Physiotherapy for People Experiencing Long COVID Chapter](#). If you have any additional feedback, suggestions or recommendations to help us improve this chapter, please email the editors at [\*\*covidtextbook@deakin.edu.au\*\*](mailto:covidtextbook@deakin.edu.au).

## References

## PART IV

# PERSONAL FACTORS

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.

Personal factors are recognised within the International Classification of Function; however, they are not included in the formal classification system (i.e. the chapters referred to in other sections of this textbook). While they exist independently of health conditions, these factors influence how the individual experiences disability and some (such as age and gender) are often included in data collection. Other personal factors may include ethnicity, Indigenous status, educational level, socio-economic status etc.



## PART IV

# PERSONAS

If this is your first visit to the textbook, please take a moment to read the [About This Book](#) chapter to get the most out of your experience.





## 5. An introduction to personas

*By Danielle Hitch*

As interventions for people recovering from COVID-19 evolve, delivering patient-centred care becomes an increasingly important aspect of best care. Understanding the needs and preferences of patients is critical to designing care plans and healthcare services that meet their needs and expectations.

### *What are personas?*

Personas are tools for gaining a deeper understanding of patients and their unique perspectives. They are created to represent different types of people who might use a particular product or service. In healthcare, personas are created to represent patients, caregivers, and other stakeholders who interact with healthcare services. They are detailed descriptions of a person and their experience with a specific health condition (in this case, Long COVID). The following chapters provide a series of personas on the 'people' used in many of the learning and reflective activities within this textbook. Please watch the following brief video for examples of how personas can support business owners in designing their marketing strategies.



*One or more interactive elements has been*

*excluded from this version of the text. You can view them online here: <https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=387#oembed-1>*

“[Personas](#)” by [DIY Toolkit – YouTube](#) is licensed under CC BY 3.0.

Personas are also used as a basis for improving healthcare services. They are not meant to represent any specific individual but are a combination of characteristics, symptoms and issues typically experienced by a category of person. Personas are fictional representations of individuals or groups that are based on research and data.

### *How were the personas in this textbook created?*

All of the personas in this textbook were co-authored by a person with Long COVID (also known as a lived experience expert). These co-authors responded to an expression of interest circulated on social media and were paid for their time and expertise. As part of our commitment to transparency when working with co-authors, a memorandum of understanding was developed listing mutual expectations and arrangements for signature before the commencement of writing. All co-authors chose from a list of proposed personas but were also able to suggest other ‘people’ they would like to develop. The proposed personas were developed by the editorial team to ensure we provide readers with a diverse range of ‘people’ with which to practice their new skills.

The lived experience co-authors then completed an online template providing major headings and prompts to develop the details of their persona. They were also given a choice of three photographs to represent their ‘person’ and were free to

add in as much or as little detail as they wished. The project team then wrote up a full draft of the persona, founded on the template information but also incorporating findings from qualitative research and other evidence. The draft of the persona was then returned to the lived experience co-author for review, at which point they were free to make any changes, additions or subtractions they wished. With their approval, the finalised persona is then published in this textbook.

## *What do personas offer?*

Personas have the potential to contribute to multiple aspects of healthcare. They can be used in healthcare education to design learning experiences that meet the unique needs of different types of learners. For example, a persona representing an older patient



*[“Personas entretenimiento”](#) by Donna Hughes is licensed under [CC BY SA](#).*

with dementia living in a residential care home could be used to design educational materials that develop the skills of occupational therapy students working with this patient population. Personas can also be used in healthcare service delivery to design services that meet the unique needs and preferences of patient groups. In this textbook, the personas represent a range of lived experiences for people living with Long COVID. Apart from providing a basis for learning and reflective activities, they could also be used to design healthcare services tailored to the needs of this group of patients.

## *What are the benefits of using personas?*

Personas can;

- Provide a deeper understanding of patients and their unique perspectives.
- Support empathy for patient needs and experiences among health professionals, other caregivers and other stakeholders.
- Enable the design of relevant, effective and accessible healthcare services.
- Improve patient satisfaction and outcomes.
- Provide a framework for decision-making that assists services in making informed choices aligned with patient preferences and goals.
- Promote cultural competency by exposing health professionals and other caregivers to the experiences of patients from different cultural backgrounds.
- Support interprofessional collaboration by developing a shared understanding of patients among different healthcare professionals.
- Help to identify gaps in service delivery by highlighting unmet patient needs or preferences.

## *What are the limitations of personas?*

Personas can;

- Become misleading or present an unrealistic vision of patient needs if they don't have a basis in experience and data.
- Require periodic updates as patient groups change and new priority patient groups emerge.
- Not be the sole source of decision-making, which needs to

also be supported by other data and inquiry.

- Be less engaging and less successful as a tool for design and development when they lack a description of the needs and preferences of patients, and focus only on processes or procedures from the health service perspective.
- Never substitute for building and maintaining a relationship with a real-life patient.

### *How to use the personas in this textbook.*

The personas presented here have two main functions. The first is to provide a foundation for the learning and reflective activities within this textbook. The second is to provide a resource for use by readers in other contexts. Under the provisions of the Creative Commons licence for this textbook ([CC-BY-NC-4.0](#)) you can share (copy and redistribute the material in any medium or format) and adapt (remix, transform, and build upon the material for any purpose) these personas for your own purposes. For example, you could rewrite sections of the personas to make them more relevant to your local community or choose elements of them as inspiration for development activities.

The only condition for using the personas is that you display the attribution of our work whenever you use it. This should take the form of “Name of Persona [Hyperlinked to first page of the Persona]” by “Name of Authors” is licensed under [CC-BY-NC-4.0](#).

We hope you enjoy reading and applying these personas as

much as we have thoroughly enjoyed creating them. If you have any suggestions for future personas or would like to collaborate with the editorial team on creating one, please contact us at **[covidtextbook@deakin.edu.au](mailto:covidtextbook@deakin.edu.au)**.

## 6. Gayle Smith

*By Bernadette  
O'Shannessy & Danielle  
Hitch*



**Gayle Smith and her garden.** Photo by [Brenkee](#) from [Pexels](#).

Gayle is a 65 year old woman from an English speaking Anglo-Australian background. She has always been passionate about social justice and has had a long career with not-for-profit and charity organisations as an advocate and activist for people experiencing disadvantage. Gayle is a dedicated gardener and is currently transitioning her garden to drought-resistant native plants. Gayle also enjoys the arts, particularly live music and theatre productions. She has been in a long-term relationship with Jenny for the past 30 years, and they spent most of their life together in a larger rural town two hours east of their current location. They have a cat called Mickey, but Gayle is a self-described 'dog person' and doesn't spend much time with him.

***"I know life wasn't meant to be easy, but in a country like Australia it should at least be fair."***

### **Home Life**

Gayle lives with Jenny in a two-bedroom unit close to the centre of their town. It is also within walking distance of the lakefront and the bridge, which leads to an ocean beach. Jenny (aged 70) had a long career as an accountant and ran a busy and very successful practice. They downsized when they moved seven years ago and own their unit outright. Both Gayle

and Jenny receive the Aged Pension, and their finances are, therefore, somewhat constrained. However, she ensures they have access to all their entitlements, and her partner's professional background helps them to live within their means. Their home is in good condition, but both find home maintenance tasks harder as they age.

Gayle's two older brothers are farmers in regional Victoria but are over three hours away by car. She sees them two or three times a year and really enjoys catching up with her nieces and nephews face-to-face. She frequently uses Zoom to keep in touch with her extended family and is active in social justice groups on several social media platforms. One of Gayle's closest long-term friends (Cathy) lives five minutes away, and they used to have dinner every week with her and her husband (Gary) at the local bistro. However, Cathy and Gary moved into aged care six months ago due to their respective health issues, and they can no longer participate in many community activities. Despite making a conscious effort when they arrived in town, Gayle and Cathy have no other close friends locally but do have a wide range of acquaintances. However, Gayle has several online friends with shared interests with whom she keeps in regular contact.

***"It's hard making new friends at our age, but we've got each other, and that's enough."***

### Community



**Lakes Entrance.** Photo by [Alex Proimos](#), [CC BY 2.0](#), via [Wikimedia Commons](#).

Gayle and Jenny moved to Lakes Entrance seven years ago from their original home in Traralgon. The move coincided with Jenny's retirement, and they were attracted to the natural beauty, laid-back atmosphere of the town and the chance to spend more



time with Cathy and Gary. Lakes Entrance has a population of around 8,600 people and is a growing community, including many retirees. The town attracts tourists in the summer when up to 50,000 additional people visit the area to take advantage of the lake system and Ninety Mile Beach. Gayle has mixed feelings about this influx of tourists – while they add a lot of colour and buzz to her town, they also place a significant strain on local services and facilities.

Lakes Entrance has a community health clinic with a wide range of services and two other general practitioner (GP) clinics, but the nearest hospital is 40 kilometres away in Bairnsdale. The town has three supermarkets, numerous general shops and a wide selection of cafes. Many kilometres of parkland are in the immediate surrounds, and a council-run Aquadome with indoor heated pools.

Gayle has lived in the Gippsland region all her life and grew up in Moe. She left school at 16 and worked in several administration and secretarial positions before moving to Traralgon in her early twenties. Over time, she developed further skills in welfare and community development, which became the focus in the second half of her career. Gayle worked for several non-profit welfare organisations in the region and deeply enjoyed supporting local people to overcome social disadvantages and improve their quality of life. She continued to work casually as an equality advocate for a regional organisation. She enjoyed the challenge of working with the different issues experienced by the residents of this smaller community. Gayle was also on the board of several local community organisations and had meetings to attend in these roles on a weekly basis. She and Jenny also developed links with [the local branch of the University of the Third Age \(U3A\)](#), which provides courses and social activities for people over 50 who are retired or semi-retired. They visited the Senior Citizens Club on several occasions but chose not to join as they weren't interested in many of the activities on offer.

***“The Club just does nice, sedate activities for old people... I know I’m old, but I guess I don’t want to be a typical old lady.”***

### **Health**

Gayle was a healthy and active young child who loved rough and physical play with her brothers. She contracted polio at the age of 4, in one of the last outbreaks following the introduction of vaccinations. During the acute phase of her illness, her lower limbs became paralysed, and she spent many months in a Thomas Splint, which kept her lower limbs immobilised. Overall, she spent ten months in a hospital in Melbourne with limited visits from her parents or other family members due to its distance from home. She has few memories of her time in the hospital besides feeling happy while sitting in the sun on an open-air balcony with other children. However, Gayle clearly remembers the day she came home from the hospital and how her mother cried joyfully at her return. Gayle also required ongoing rehabilitation for the next three years, which she received at the local hospital. She was left with residual lower limb bilateral weakness and used orthoses (called callipers) and crutches to support her mobility until she contracted COVID-19. Despite her physical disability, her family expected her to participate in community life fully and encouraged her to “*be the same as every other kid*”.

***“I don’t think they quite understood how hard it was for me sometimes, but their positive attitude gave me confidence.”***

## *Polio in Australia*

For more information about the experience of Australians during Polio outbreaks, please read:

["Defining moments: Polio vaccine introduced in Australia"](#) from the National Museum.

["Remembering Australia's Polio scourge"](#): from the University of Melbourne

Besides her physical disability, Gayle has experienced good health throughout her life. She always prioritised and was mindful of her well-being by maintaining a good diet and as much physical activity as possible. Gayle is an NDIS participant but only uses the scheme to support and fund her orthoses. She only sees a GP two to three times per year for routine queries. Since moving to Lakes Entrance, she has found it difficult to maintain continuity of care with a local doctor. In common with many rural towns, there is significant



**Gayle as a young woman.** Photo by unknown. All reasonable efforts to discover the rights holder have been made. If you are the rights holder, please contact [copyright@deakin.edu.au](mailto:copyright@deakin.edu.au).

turnover in staff, and she never seems to see the same clinician twice. Gayle maintained her usual activities as much as possible during the initial lockdowns in 2020. She was thankful that her regional community was not subjected to the same strict restrictions as metropolitan Melbourne.

Gayle has experienced disability discrimination throughout her life, including exclusion on the basis of stigma and physical environment barriers. She found this very distressing as a younger person but has reluctantly accepted that this is often part of daily life for people with disability.

***“I can pretty much look after myself, but I wish I didn't have to go through my whole life story every time.”***

**COVID-19**

## Acute Infection



**Gayle's shoulder fracture.** Photo by [RSJThompson](#), [CC BY-SA 3.0](#), via [Wikimedia Commons](#).

Gayle acquired COVID-19 in a Melbourne hospital, where she had been admitted following a serious injury. During a visit to the supermarket, her crutch slipped on a spilled drink at the local shopping centre and fell heavily. She badly fractured her proximal humerus and was transported by ambulance to Bairnsdale Hospital. Doctors determined she required

specialist orthopaedic care due to the severity of her fracture, and she was transferred to a major tertiary hospital in the city.

Gayle had surgery to repair her fracture and made an excellent recovery over eight days. The team planned to discharge her home in the next 24-48 hours once community-based rehabilitation and follow-up care had been arranged. However, on the ninth day of her admission, she began to develop respiratory symptoms and headaches. The hospital soon identified an outbreak of the Delta strain of COVID-19 on the ward, which eventually affected five patients and twelve staff members. While Gayle understood the ward team were doing their best, Jenny was extremely angry that she got COVID-19 in *"the very place she should be safest"*. After several angry conversations with the ward staff, she was banned from calling in, and Gayle only received phone calls from her brothers once or twice a week.

Gayle's symptoms were relatively acute and mild, and most of her respiratory symptoms resolved within the first four days. However, she continued to experience dizziness, breathlessness and increasingly extreme fatigue for the rest

of her admission. Following COVID-19 regulations, Gayle remained isolated in the hospital for 14 days following her positive PCR test. No visitors were allowed due to high levels of community transmission, and Gayle felt very alone and bored. Her only contact with Jenny was by phone or video call, although the second option was only available when staff had enough time to facilitate the calls (which was rarely). Gayle was referred to the psychology and pastoral care services after the treating team noticed her becoming increasingly despondent, which she found supportive and helpful.

During her extended admission, Gayle developed deconditioning and could not participate in the usual post-surgery rehabilitation regime with physiotherapists and occupational therapists. She was therefore discharged back to Bairnsdale Hospital for a further stay in [the inpatient rehabilitation ward](#). She found this admission a far more positive experience, as she had more contact with Jenny, and the ward encouraged her to be as active as possible. Gayle continued to experience general weakness and breathlessness and could only stand and walk for up to a minute at a time. The treating team was confident that her other symptoms (dizziness, fatigue and headaches) were due to her ongoing COVID-19 recovery compounded by her recent shoulder surgery. She achieved most of her rehabilitation goals within ten days and was finally discharged back home to Lakes Entrance. At discharge, she continued to use a manual wheelchair for the majority of her mobility but was encouraged to gradually increase her use of her usual mobility aids (orthoses and crutches) day by day until she regained full-time use of them.

### **Developing Long COVID**

Gayle continued her rehabilitation at home, with Jenny reminding her and helping her stick with her regime of home exercises. Two months after returning home, the dizziness had thankfully resolved. However, they both noticed that her

mobility and endurance were not improving as time passed, and breathlessness remained a persistent problem. Gayle continued to experience constant dull headaches, fatigue, constipation and post-exertional malaise, severely limiting her function and participation. She also felt she was having more trouble paying attention and remembering things, which Jenny had also observed. Gayle's standing and walking tolerance remained less than five minutes, and she needed several rest breaks to complete relatively brief activities such as showering and dressing. When she engaged in an activity (standing or seated) for more than five minutes, she rapidly became completely exhausted and needed to return to bed for several hours. The local health service provided some ongoing allied health support, but none of the treatments or strategies they implemented seemed to have any effect. Jenny remained positive and hopeful of improvement, but providing all of Gayle's care meant she no longer had time for her health or well-being. She worried about leaving Gayle alone for any length of time as she depended on her for all activities and kept putting off GP visits for her health concerns.



**Jenny started to research Long COVID online.** Photo by [David Tett, CC 0](#), via [Centre for Ageing Better](#).

Three months after Gayle's discharge from Bairnsdale Hospital, Jenny arranged for an extended consultation with a local GP she had seen in the past. She observed that Gayle appeared very flat and was not as well groomed as usual. The GP gently attempted to discuss her

mood, but Gayle refused to engage, saying, *"You think its all in my head – I'm not making this up"*. Jenny had done some online research into COVID-19 recovery and raised the possibility of Long COVID. The GP told them Long COVID only applied to people with no previous health issues, while her

disability could explain the problems Gayle was experiencing. She wondered whether Gayle had developed post-polio syndrome, which would explain her muscular weakness, and suggested she refer her to a neurologist. Gayle knew a few people online with post-polio syndrome and told the GP she didn't think her experiences lined up with theirs. However, the GP proceeded with arranging the referral and asked her to continue with her exercises and rest whenever she felt like it. She also told Gayle to try and reduce the amount of Panadol she was taking for her headaches as it may be causing her constipation and suggested she spend more sitting out in her garden as the weather warmed up.

When Jenny followed up on the referral one week later, she was told the waiting list for a consultation was currently nine to twelve months. She also contacted NDIS on Gayle's behalf to request increased support, and additional home help and community access services were arranged. However, they struggled to find any carers available for the community access services in the local area, so these are yet to commence. Funding for the limited allied health follow-up they received from the local health centre ended, and Gayle and Jenny began to feel abandoned and increasingly alone. The only positive aspects they could see in their situation were that Gayle's symptoms were not getting any worse, and their relationship was as strong as ever.

***"I'm just stuck. Nothing is changing; I'm not getting better, not even slowly."***

### **Current Situation**

Gayle's mobility and endurance remain limited, but she can now undertake activities for around 15 minutes. She has learnt a lot about energy conservation techniques online, is skilled at scheduling rest breaks and continues to use a wheelchair for the majority of her mobility for this reason. However, she finds the need to take her time completing activities extremely frustrating, and sometimes she gives up and asks Jenny to



finish them. Her dull headaches, breathlessness during activity and post-exertional malaise remained unchanged, although she had managed to relieve her constipation by increasing fibre in her diet. However, she still uses painkillers on a daily basis, as she has not found a non-pharmaceutical strategy that works for her. Gayle reports feeling 'muddled' and finds it hard to focus on daily tasks. This also causes problems when she participates online in social justice forums and family discussions, as she sometimes finds reading posts (particularly when they are numerous) overwhelming. While Jenny reports that Gayle has problems with attention, she hasn't observed any problems with her memory. Jenny also believes there has been a small improvement in Gayle's attention.

One positive development has been the resumption of her casual role as an equality advocate, which she resumed approximately six months after returning home. Her employer has negotiated for her to complete up to five hours per fortnight and ensures the tasks she is given can be completed flexibly and remotely. They also understand if Gayle completes fewer hours if she finds her symptoms harder to deal with, and they are committed to retaining her as they value her so highly. She has also resumed serving on two boards for community services, facilitated by the fact their meetings have now moved online. Gayle has tried to increase her time in her garden but says she often ends up in tears of frustration about the things she can no longer do. Most of the garden is also inaccessible to her wheelchair, which means she can access it even when she has enough energy. Gayle feels very self-conscious about others seeing her in her wheelchair as they walk past, saying, *"Everyone just looks at me and thinks – oh, that poor old crippled woman"*. She has had to decline regular invitations to pick up casual hours as an equity advocate, as she doesn't feel able to do this any more.

Jenny continues to provide significant care for Gayle and rarely leaves the house to participate in community activities.

This is having an increasing impact on her own health, as she has put on some additional weight and deeply misses engaging with nature on her formerly regular walks. They are still waiting to hear about the proposed neurology appointment, but when Jenny enquired recently, she was told it was still at least six months away. Her initial optimism about Gayles's recovery has now evaporated, and she is becoming increasingly resigned to being Gayles's carer for the rest of their lives together.

***"I used to be proud of my memory and would be sure I had remembered rightly; now, if I am questioned, I assume I could have remembered wrongly".***

### **Life Roles**

The prolonged symptoms Gayle is experiencing following her COVID-19 infection have clearly had a major and widespread impact on her life. She feels very isolated and lonely and tremendously guilty about all that she feels Jenny has had to give up to care for her. She yearns to get back to walking along the lake and beach together and worries that Long COVID will blight the rest of her remaining years.

***"I tire very easily and need lots of rests. If I've done something big, like going to the cafe, I might most of the next 24 hours to recharge... and that's just too long."***

Role	Before COVID-19	Currently
Worker	Gayle worked casually as an equality advocate, up to 15 hours per week.	She did not work for six months and works remotely for up to 5 hours a fortnight.
Home Maintainer	Gayle shared household tasks with Jenny and completed them all independently.	NDIS support workers provided some assistance, with Jenny assuming responsibility for all remaining tasks.
Friend	Gayle had one close friend who had recently moved into aged care. She and Jenny shared many acquaintances in Lakes Entrance, and Gayle had several online friends she regularly contacted.	Her social network mostly consisted of Jenny for the first six months after discharge from the hospital, with some sporadic contact with online friends. However, in recent weeks, she has begun reconnecting with her online friends and managed a very brief visit to Cathy and Gary in the local aged care facility.
Family Member	Gayle saw her brothers, nieces and nephews two or three times yearly, mostly by travelling up to their properties. She also frequently used Zoom to socialise with extended family.	She no longer visits her brothers face to face and relies on phone contact with them. She is beginning to increase her use of Zoom to keep in touch with other family members. Still, she and Jenny have not attended any recent family occasions (i.e. Easter, Christmas, weddings).
Informal Organisation Member	Gayle maintained a regular social media presence on social justice forums, and she and Jenny would support grassroots community organisations whenever they could.	She has resumed participation in online forums (albeit to a lesser degree than previously), but is yet to reconnect in person with local grassroots groups.

Caregiver	<p>Gayle provided minimal care to Jenny as they were both healthy and independent. She occasionally cared for her brothers and would stay with them from time to time to help out when needed (i.e. around harvest). She also provided professional caregiving in her community as part of her employment.</p>	<p>Her ability to care for others is now limited to emotional support, as she cannot undertake any significant physical tasks. Gayles feels the loss of this role particularly keenly.</p>
Volunteer	<p>Gayle was a board member of four local community organisations, contributing her equality and social justice expertise and experience.</p>	<p>Gayle has resigned from two of the boards, as the meetings are in person, and she does not feel able to participate. However, she continues to serve on two other boards that meet remotely.</p>
Community Member	<p>Gayle and Jenny recently visited cafes, movies, local festivals and shows in Lakes Entrance and the local area.</p>	<p>Gayle has resumed going for the 'quick' coffee at a nearby cafe, but Jenny finds pushing her there and back very tiring as the footpaths are not very accessible. Still searching for NDIS carers who can support community access activities.</p>


## Activities of Daily Living

Many of Gayle's activities of daily living have also changed a lot since she acquired COVID-19.

***"I am more of a chatter than a doer these days, and that's not like me at all."***



An interactive H5P element has been excluded

 from this version of the text. You can view it online here:

<https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=212#h5p-5>

**Rebel for Life.** Photo by [In-Press Photography](#), CC 0, from [Centre for Ageing Better](#). / **Doing the laundry.** Photo by [Sarah Chai](#) from [Pexels](#) / **Family Birthdays.** Photo by [Vlada Karpovich](#) from [Pexels](#).

Activity	Before COVID-19
Showering / Bathing	Independent and has always used a shower stool. The bathn bathtub.
Toileting	Independent.
Walking / Moving Around	Independent using orthoses and crutches. Able to walk any
Dressing	Independent and has always completed this task in sitting.
Driving / Public Transport	Independent using public transport. Previously had a drivin sold this prior to moving to Lakes Entrance.
Safety / Emergency Management	Independent for all tasks.
Meal Preparation	Independent, and shared this activity with Jenny.
Shopping	Independent, and shared this activity with Jenny. One or bo day, as they preferred to do 'small shops' to take advantage
Community Participation	Independent and able to access all local facilities.
Rest / Sleep	Independent. Gayle maintained good sleep hygiene practic per night.
Caring for others	Independently able to care for others both physically and en
Play / Leisure	Independently maintained her garden, participated in onlin

## Gayle's Goals

Gayle wants to work on her recovery from Long COVID but doesn't know where to start or what other options could be helpful. She would like help with the following goals (but is yet to prioritise them):

1. Return to her previous level of casual work as an equality advocate.
2. Resume attending in-person board meetings and returning to the boards from which she has resigned.
3. Regaining the ability to use her orthoses and crutches for

all mobility.

4. Increase participation in domestic tasks to reduce the carer burden on Jenny.
5. Visit the lake or beach at least twice a week with Jenny.
6. Participation in community activities in Lakes Entrance at least twice a week, either alone or with Jenny.

***“I love being out and about and spending time with others. After lockdown and all this, home feels like a bit of a prison.”***

## What does the evidence say?

### **The current evidence base**

- The most relevant evidence for this case relates to the symptom profile and interventions targeted at specific symptoms.
- Currently, no evidence is available specifically about the impact of Long COVID on the LGBTQI+ community or people with a history of polio.

### **Many characteristics compound the risk of developing Long COVID.**

- A statistically significant increased risk of mental health issues, fatigue and Long COVID symptoms overall was identified for women in a recent international systematic review and meta-

analysis of 13,340 cases<sup>1</sup>.

- A higher proportion of women who are older, white and/or have pre-existing chronic conditions or disabilities report prolonged symptoms following COVID-19 infection<sup>2</sup>.

**Long COVID symptoms can occur in recognisable clusters.**

- 'Brain fog' frequently occurs in a cluster of symptoms, including fatigue, dizziness, myalgia, word-finding difficulties, and memory impairment<sup>3</sup>.
- Both headaches and dizziness are common neurological symptoms of Long COVID and significantly impact people's quality of life<sup>4</sup>.

1. Maglietta, G., Diodati, F., Puntoni, M., Lazzarelli, S., Marcomini, B., Patrizi, L., & Caminiti, C. (2022). Prognostic Factors for Post-COVID-19 Syndrome: A Systematic Review and Meta-Analysis. *Journal of Clinical Medicine*, 11(6), 1541. doi: 10.3390/jcm11061541.
2. Thompson, E., Williams, D., Walker, A., Mitchell, R., Niedzwiedz, C., Yeang, T., ..... & Steves, C. (2022). Long COVID burden and risk factors in 10 UK longitudinal studies and electronic health records. *Nature Communications*, 13, 3528.
3. Jennings, G., Monaghan, A., Xue, F., Duggan, E., & Romero-Ortuño, R. (2022). Comprehensive Clinical Characterisation of Brain Fog in Adults Reporting Long COVID Symptoms. *Journal of Clinical Medicine*, 11(12), 3440. doi: 10.3390/jcm11123440.
4. Rodríguez-Pérez, M. P., Sánchez-Herrera-Baeza, P., Rodríguez-Ledo, P., Serrada-Tejeda, S., García-Bravo, C., & Pérez-de-Heredia-Torres, M. (2022). Headaches and Dizziness as



- Older adults are more likely to have symptoms post-COVID-19, most commonly fatigue, dyspnea, cough and arthralgia. This age group appears more likely to experience pulmonary symptoms than young people <sup>5</sup>.

### **Rural, Regional and Remote Areas.**

- There is limited availability of multidisciplinary care and care providers in regional and rural areas, which is a longstanding structural barrier to health equity <sup>6</sup>.
- A review of sustainable telehealth in Australia has identified five key long-term requirements – developing a skilled workforce, empowering consumers, reforming funding, improving digital ecosystems and integrating telehealth into routine care <sup>7</sup>.

Disabling, Persistent Symptoms in Patients with Long COVID—A National Multicentre Study. *Journal of Clinical Medicine*, 11(19), 5904. doi: 10.3390/jcm11195904.

5. Daitch, V., Yelin, D., Awwad, M., Guaraldi, G., Milić, J., Mussini, C., ... & Abecasis, D. (2022). Characteristics of long-COVID among older adults: a cross-sectional study. *International Journal of Infectious Diseases*, 125, 287–293. doi: 10.1016/j.ijid.2022.09.035.
6. Hale, N., Meit, M., Pettyjohn, S., Wahlquist, A., & Loos, M. (2022). The implications of long COVID for rural communities. *Journal of Rural Health*, 38(4), 945–947. doi: 10.1111/jrh.12655.
7. Thomas, E., Haydon, H., & Smith, A. (2020). Building on the momentum: Sustaining telehealth beyond COVID-19. *Journal of Telemedicine and Telecare*, 28(4), 301–308. doi/10.1177/

### Further information.

- Hitch, D., Yashadhana, A., & de Leeuw, E. (2022). [First, COVID hit disadvantaged communities harder. Now, long COVID delivers them a further blow.](#) The Conversation, June 20.
- Stewart, R. (2021). [Post-pandemic rehabilitation needs in regional, rural and remote Australia.](#) Partyline, March18.

## References

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# 7. Jarrod Micallef

*By Tara Barton & Danielle Hitch*



**Jarrod Micallef.** Photo by [Tima Miroshnichenko](#) from [Pexels](#).

Jarrod is a 42-year-old man who lives in the inner-city suburb of West Hobart. His mother and father were born in Australia. His father's family migrated from Malta following World War II, and his mother's family lived in Tasmania for many generations. Jarrod is a self-employed painter and decorator, and he has just taken on a first-year apprentice (Tyson). He loves to ride, run and hike in the bushland and parks around the city. Jarrod is also a member of the local amateur

Australian Rules Football team called the West Hobart Warriors.

***"I'm a simple bloke – all I need is footy and the great outdoors"***

## Home Life

Jarrod is single and lives alone after his divorce from his wife (Emma, aged 40) around three years ago. They share three children (Olivia, aged 9; Harry, aged 7; and Ava, aged 4) and

co-parent successfully as they live in the same neighbourhood. He left school at 16 to begin his painting and decorating apprenticeship and has owned his successful business since the age of 23. Jarrod has a reputation for being a reliable and skilled painter and has built a loyal customer base over the years. He met Emma in high school, and they married as soon as he finished his apprenticeship. After years of trying to start a family, they saved up enough money to undergo in vitro fertilisation (IVF) to support all three of their pregnancies. Their marriage ended amicably, and they remain on friendly terms.

Jarrod inherited his house from his grandmother and has been renovating the property since moving in two years ago. He sees his parents (who also live nearby) at least once a week but rarely sees his brother, who lives in the North West of Tasmania with his young family. Emma is an aged care worker in a local nursing home, and despite the challenges, she thoroughly enjoys her job.



**Emma, Olivia, Harry and Ava.**

Photo by [Dario Moscato](#) from [Pexels](#).

She is in the second year of Nursing at the University of Tasmania and juggles her working hours around her course, job, and childcare responsibilities. Olivia and Harry attend the local state primary school, while Ava splits her time between kindergarten (2 days per week) and childcare (3 days per week). Jarrod is generally able to arrange his work around Emma, and their flexible custody arrangements mean their children are always with one or the other parent.

***“All in all, we are doing OK. We may not be together anymore, but we’ve got to work as a team for the kids”***

## Community

West Hobart is close to the CBD of Tasmania's capital city, Hobart. Due to its location, Jarrod can walk to most local conveniences, and he occasionally uses public transport in preference to driving his trade van. All their children's friends live within close proximity, and his social network encompasses friends from school, Park Run and his football club. Jarrod wishes he could be more active in the community (particularly in groups that support sports and green spaces), but his jobs don't leave much spare time.



**Mellifont Street, West Hobart.**

Graeme Bartlett, [CC BY-SA 3.0](#), via [Wikimedia Commons](#).

The suburb includes a mix of modern and historic homes and has experienced gentrification in recent years due to its prime location. The suburb is known for its friendly community, an abundance of parks and recreational facilities, and a thriving arts and cafe culture.

Jarrod feels very lucky to live in such a nice neighbourhood, which would not have been possible without the inheritance from his grandmother. However, he is conscious that his house is not as well kept as the others in his street, prompting him to renovate the property room by room.

***“They say you should have the worst house in the best street, but I know it looks scruffy”***

## Health

Before the COVID-19 pandemic, Jarrod had always been relatively fit and healthy. A notable feature of his medical history was a very rare drug reaction he experienced in childhood, which resulted in an extended hospital admission. After being prescribed penicillin for an ear infection, Jarrod developed Stevens-Johnson Syndrome (SJS) with widespread blistering and peeling of the skin and mucous membranes. He has been left with some scarring on his abdomen but does not appear to have suffered any longer-term issues. Jarrod has, however, been told there is a small risk of re-occurrence every time he is prescribed a new medication.

Jarrod is extremely avoidant of medical attention for any illness or injuries as he finds this extremely anxiety provoking. His reluctance to seek help when unwell greatly concerns Emma and his parents, who worry that he may miss opportunities to identify and treat problems early as he ages. In more recent years, Jarrod has noticed more joint pain in his knees and lower back, which he attributes to the physical nature of his work as a painter and ongoing involvement in football. This pain had been becoming more persistent (particularly in the colder weather), and Jarrod was managing this with a combination of Deep Heat and glucosamine.

***“I can handle this myself – I don’t need some doctor making a mistake and setting all that off again”***

## COVID-19

### *Acute Infection*

Jarrod caught COVID-19 in early April 2020 from one of his customers who had just returned from visiting family in the

Northwest of the state. While the community was becoming more aware of COVID-19, there were no coordinated testing sites available, and knowledge of the virus was generally very poor. Jarrod woke up one morning with a terrible migraine (which he rarely experiences) and took two Panadol before driving to work. However, after picking up Tyson and heading to his current job (repainting a heritage property), he suddenly felt incredibly fatigued. Jarrod ended up sleeping in the van while Tyson continued painting the house. Upon returning home, he went to bed immediately and began sweating profusely. After tossing and turning all night, he went to Emma's to pick up the children for school. There he noticed his morning coffee tasted completely different, and he couldn't smell Emma's cooked breakfast. He fell asleep with his head on the kitchen table about 5 minutes after sitting down to drink his coffee, and when Emma took his temperature, it was almost 40C.

After she dropped the kids at school and kindergarten, Emma cancelled her work shift and convinced Jarrod to come with her to the emergency department of Hobart Hospital. Upon arrival, the emergency department staff quickly identified Jarrod



**Royal Hobart Hospital.** *Wikian,*  
[CC BY-SA 3.0](#), via [Wikimedia Commons](#).

as a possible COVID-19 case and significant infection prevention measures were put into place. He sensed the staff were panicking somewhat and had a panic attack in response to his own anxiety about being in the hospital. Jarrod tried to convince the nurses that he should be discharged home, who responded by stationing a security guard at his door for the remainder of his admission. He stayed at the hospital for five days until his fever broke before being deemed well enough to go home. He was transported home from the hospital by non-

emergency paramedics in fully Hazmat personal protective equipment and saw some of his neighbours watching his arrival. No one could visit Jarrod in the hospital, and access to phone contact was very limited. None of his contacts (including Emma and the kids) subsequently tested positive for COVID-19.

Upon discharge, Jarrod isolated himself in his home and conscientiously followed all directions from the authorities. Emma dropped food and other supplies at the door wearing a mask and gloves, but he asked his parents to stay away, given their age and his father's failing health. Jarrod's fever had abated somewhat; however, he continued to have spikes in temperature over the next ten days. He felt tightness in his chest and was breathless, but while this was uncomfortable, he felt confident it would resolve due to his overall fitness. Jarrod's smell and taste remained disordered, and he had to force himself to eat. He subsequently lost 7 kilograms over two months. Jarrod felt too unwell to work for three weeks, but after that, he returned to work with Tyson. He felt OK overall, and the only remaining symptoms were mild fatigue and an ongoing loss of smell and taste.

## ***Developing Long COVID***

Jarrod knew his recent COVID-19 infection gave him some immunity, but he stayed home as much as possible to reduce the risk of passing an infection on to other family members. He was particularly careful to protect the kids from exposure, as both girls had asthma, and their son experienced recurrent chest infections. Jarrod returned to Park Run and the football club, joking, *"at least I'm bulletproof because I got it out of the way early"*. However, when stories began to emerge of people being re-infected, he minimised his interaction with others in the community. While some of his friends supported this choice, others (including Jarrod's parents) thought he was



*“going over the top”* and expressed disappointment and concern about the impact this might have on his kids.

***“They just don’t get it ... they haven’t lived it yet.”***

After being back at work for a month, Jarrod suddenly experienced a noticeable increase in his knee and back joint pain. He also began to experience new symptoms – increasing muscle pain occurring all over his body, swollen and bloodshot eyes, and dry skin. He also felt his ears were ‘full’ and began experiencing transient episodes of dizziness. Jarrod wondered if this was due to his COVID-19 infection or whether he had picked up another virus from somewhere. He did not seek medical treatment and continued to try and work full-time, but his new symptoms (particularly his worsening muscle pain) began to impact his daily life severely. After doing his own research, Jarrod began to wonder whether he had developed ‘Long COVID’, and he began to connect with some online support groups.



**Jarrod on the job.** Photo by [Tima Miroshnichenko](#) from [Pexels](#).

Jarrold became very careful about who he told about his infection after an incident with a client. He mentioned his infection in general conversation with them, was sacked on the spot and told never to return to the house as they had a family member who was immunocompromised. Due to public health restrictions and the general impact of the pandemic, the business had dried up, and he and Tyson applied for COVID-19 Job Keeper for financial support. He felt bad about Tyson, given that he was starting his career and had nothing to fall back on. However, they were both able to continue working for lesser hours, mainly on commercial properties. Over time, Tyson began to take on more and more of the work, but Jarrold worried that he was beginning to give him too many responsibilities due to his own limitations.

Jarrold's health continued to worsen, and things came to a head when he experienced severe shortness of breath one day at work. He had been hauling some heavy storage buckets on site when his breathlessness suddenly worsened, and he was no longer able to take a deep breath. Another tradesman working on the site called an ambulance, and he was transported to the emergency department. When he gave his history to the doctor on duty, they said it probably had nothing to do with his COVID-19 infection because *"everyone gets better pretty quickly"*. However, they were able to diagnose a partial lung collapse and identified biomarkers that indicated unusual immunological responses. With his symptoms under control after a couple of hours, he was again discharged home.

***"You just never know what you're going to get with Long Covid ... and I think they just wanted to get rid of me after last time"***

From Emma's point of view, the emergency department visit had still been helpful because Jarrold now had some information on record about his post-COVID-19 health status. However, Jarrold was incredibly frustrated by the lack of response he received from the hospital and felt that he was

constantly wasting what little energy he had trying to convince others of his experience. As time wore on, any exertion or physical activity seemed to make him feel worse, which in turn also had a negative impact on his mental state. He came to believe that he wouldn't improve unless he took a complete break from work and other activities to allow himself to recuperate. So, he decided to put his business on hold for three months. He offered to pay Tyson partial wages from his own savings to keep him on, but Tyson decided to move on to another painting business, and they reluctantly parted ways. Jarrod's daily routine became much more sedentary as he slept approximately 16 hours daily and became increasingly restricted to his home environment.

## Current Situation



**Dr. Singh.** Photo by [World Sikh Organization of Canada](#) from [Pexels](#).

Three years have passed, and Jarrod continues to participate far less in daily life than before his COVID-19 infection. While some of his symptoms have now abated (like the dizziness and bloodshot eyes), overall, any improvements in his health have been very slow, and he has experienced several relapses. Jarrod still experiences daily joint and muscle pain, which he thinks has been exacerbated by not moving around as much as he used to. He deeply wants

to be well enough to rehabilitate back to running but still

experiences extreme fatigue after short walks. After encouragement from Emma, he has linked in with a local General Practitioner (Dr Singh) who has been monitoring him fortnightly and running many tests. None of the tests returned abnormal results. Dr Singh agreed to work with Jarrod around his new physical and energy limits by continuing his gentle walks, pacing daily activities and resting. Jarrod has made it clear that he is not interested in taking any medication to help with his pain and other symptoms, and Dr Singh has respected his decision.

The past three months have been very difficult on the wider family, and his relationship with Emma is under immense strain. She now does all the domestic, community and childcare tasks they share due to the kids, and she struggles to keep up with her nursing course. While she is supportive of Jarrod overall, Emma is becoming increasingly frustrated with his insistence on 'rest' and is starting to question his commitment to getting better. She also wonders whether the online Long COVID support groups he belongs to are helpful because *"they seem a bit like echo chambers at times"*. His parents are urging him to become more active and to pitch in with childcare more often. Jarrod has lost touch with many of his friends from before the pandemic, as they have all returned to their usual activities as part of the world adjusting to 'COVID normal'.

**"If I don't get this right, I will crash as soon as I get back to work and its going to be hard enough to rebuild it from the ground up as it is"**

## Life Roles

Since developing Long COVID, Jarrod has experienced changes in many of his life roles.

	<b>Before COVID-19</b>	<b>Currently</b>
<b>Student</b>	Regularly participated in trades training and worked through an online Certificate IV in Small Business.	No longer participating in any educational courses.
<b>Worker</b>	Full-time self-employed painter and decorator with a first-year apprentice.	Not currently working, and business has been put on hold.
<b>Volunteer</b>	Volunteered every week at the local Park Run event and was an active member of the West Hobart Warriors committee.	While not a player, he does small jobs for the football club (such as timekeeping and changing room assistant on match days).
<b>Caregiver</b>	Co-Parenting with his former wife (Emma) and is heavily involved in the daily life of his children. Performed domestic tasks (such as gardening and handiwork) for parents due to their age and poor health.	Only sees his children if Emma brings them to the house, which is happening less often. He is no longer able to help his parents with domestic tasks.
<b>Home Maintainer</b>	Completed all tasks independently.	No longer gardening or doing handiwork. He is able to complete light laundry tasks, but Emma and his mother often collect laundry to complete for him.

<b>Friend</b>	Friends from children's school, Park Run, football club and his work. Regularly went on bushwalking trips with friends and occasionally camping with footy teammates.	Lost touch with a lot of his social contacts. One friend from the local Park Run group has come to accompany him on some light walks, which he hopes to continue. The football club is in regular contact and goes out of its way to find ways for him to continue contributing off the field.
<b>Family Member</b>	Regularly sees parents who live locally. He has little contact with his brother and family, who live approximately four hours away. Other family members located around Australia, who he would occasionally see face-to-face at big family events.	Does not see his parents as often and feels as though his mother, in particular, is 'treating him like a child'. Brother is sympathetic to his situation, and they have been speaking more regularly on the phone. Other family members are in touch sporadically online.
<b>Hobbyist / Amateur</b>	Player for an amateur Australian Rules Football team (West Hobart Warriors). Enjoyed cycling, running and hiking.	Not playing football currently. Able to walk relatively short distances, but not currently cycling, running or hiking.
<b>Informal organisation member</b>	Not applicable	Member of two Long COVID online support groups, with whom he connects daily.
<b>Community member</b>	He had regular informal contact with his elderly neighbour, who knew his grandparents well and had known Jarrod since he was a baby. Jarrod would often help him with odd jobs and gardening.	Neighbour drops in every 1-2 weeks for a coffee and a chat. Sometimes they do light gardening (approximately 30 mins) in each other's backyards.

## Activities of Daily Living

Along with these changes in his life roles, Long COVID has negatively impacted many of Jarrod's activities of daily living.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=812#h5p-31>

**Renovations.** Photo by [Tima Miroshnichenko](#) from [Pexels](#). / **Backyard Tomatoes.** Photo by Juan Carlos Fonseca Mata, [CC BY-SA 4.0](#), via [Wikimedia Commons](#). / **Park Run.** Photo by Paul W, [CC BY-SA 4.0](#), via [Wikimedia Commons](#).

	Before COVID-19	Currently
<b>Showing / Bathing</b>	Independent with no difficulties.	At his worst, Jarrod was unable to shower regularly due to the impact it had on his fatigue and pain levels. Can now complete this activity most days, but it takes much longer as he tries to avoid exacerbating his symptoms. Joint and muscle pain makes it difficult to hold his hands above shoulder level and to bend down to wash his lower body. Renovations on the house had stopped before completion, meaning his bathroom remains barely functional.
<b>Toileting</b>	Independent with no difficulties.	Transferring on and off the toilet is painful at times (particularly first thing in the morning), but able to complete this task without assistance.
<b>Dressing</b>	Independent with no difficulties.	Able to complete independently, but lower body dressing often causes pain due to reaching and bending.



<b>Eating / Drinking</b>	Independent with no difficulties.	His sense of smell has returned, but he perceived odours differently than previously (e.g. vegemite smells sweet). Taste is now closer to normal, but not entirely like before COVID-19. His food intake remains less than before, and he has not regained the weight he lost during his acute infection.
<b>Walking / Moving Around</b>	Independent with no difficulties.	Jarrold is able to mobilise around the house without difficulty but has limited endurance for longer distances in the community. Walking or standing for approximately 15 minutes also exacerbates his knee and muscle pain.
<b>Personal Hygiene / Grooming</b>	Independent with no difficulties.	Independent, but less able to hold hands above shoulder level for extended periods of time (such as when shaving).
<b>Sexual Activity / Intimate Relationships</b>	Single for the past three years. Independent with no difficulties.	Remains single and is not currently looking for a partner. Reports his libido is currently 'non-existent' and is worried that will never return.
<b>Caring for others</b>	Provided regular low-level support to parents and neighbours. He shared childcare responsibilities with his ex-wife.	No longer providing care for parents or neighbours. Emma supports him in having contact with his children as often as possible, but she is always present and often helps him with other tasks at the same time.

<b>Communication with others</b>	Independent with no difficulties.	Able to communicate independently, but Jarrod has fewer opportunities to socialize with others. He also reports that he 'can't be bothered' due to bad experiences with others who questioned the reality of Long COVID and its toll on his energy levels.
<b>Driving / Public transport</b>	Independent with no difficulties.	Very limited walking in the local community, and no longer uses public transport. Continues to drive his van short distances but prefers to get a lift from others as he often finds it hard to concentrate.
<b>Money management / Budgeting</b>	Jarrod often ran short of money for household expenses and forgot to pay bills. Prior to his divorce, Emma took full responsibility for the household budget.	He is under significant financial stress due to his significantly reduced income. Currently living on Job Seeker and continues to incur debts over time. His parents and Emma provide additional help on a regular basis in the form of small loans, none of which he has been able to repay.
<b>Home maintenance activities</b>	Independent with no difficulties	He cannot complete any home maintenance activities, meaning his house is slowly falling into disrepair. His current priorities are to clean the gutters, fix a small leak in his room and tidy up the garden. His mother or Emma collects and returns his laundry for him, as he finds hanging it on the line exhausting, and he does not have a dryer.

<b>Meal preparation / Clean up</b>	Independent with no difficulties. However, mainly consisted of microwave and simple meals, as Jarrod did not enjoy cooking.	Independent with no difficulties with microwave meals and drink preparation. Eating fast food delivered by meal delivery services when his budget allows.
<b>Safety / Emergency Management</b>	Independent with no difficulties. Able to call 000 if required. Smoke and carbon monoxide detectors have already been installed.	Independent with no difficulties. However, the smoke detector battery needs replacing. This has been alerting him frequently to burning food in the microwave (and the occasional stovetop meal he prepares) because he can't smell smoke.
<b>Shopping</b>	Independent with no difficulties	Undertaking all shopping online, which is delivered to his home. Delivery drivers sometimes help him put the heavier items away, but if not, he waits until his mother or Emma come over, and they lift them up into the cupboards for him.
<b>Taking care of your health</b>	He is very reluctant to seek medical attention and opposed to using medication to manage any of his health issues.	Sees GP on a monthly basis for monitoring and medical certificates. Jarrod has come to trust him, and they have a good relationship. He is not currently receiving any treatment or medication, as per his preference. Jarrod is interested in increasing his activity levels but doesn't know how. He feels frustrated and worried by the need to avoid pushing himself too far to prevent a relapse in his symptoms.

<b>Rest / Sleep</b>	Independent with no difficulties	Still sleeps 12-14 hours per day but acknowledges that sometimes this is due to boredom more than fatigue. Disordered sleep pattern. Sleep 3-4 hours at a time across all times of the day and night.
<b>Education</b>	Independent with no difficulties	No longer undertaking education, which is not currently a priority for Jarrod.
<b>Work (Paid or Voluntary)</b>	Independent with no difficulties	The painting business remains on hold. Jarrod retains all registrations and major equipment required but would need to fund a significant restock when he returns to work.
<b>Play / Leisure</b>	Independent with no difficulties	No longer participating in riding, running, and walking on a regular basis. A friend from Park Run visits him twice a week to walk around local streets, and they are slowly extending the distance walked (currently approximately 2 kilometres). Jarrod is wary of increasing his walking, as he has experienced 'collapses' on some occasions, which have increased his symptoms in the short term.
<b>Community Participation</b>	Independent with no difficulties	Attends football games and training when he can and has begun to take on small jobs (timekeeping) when he is having a good day. Feels connected to and supported by the club.

<b>Family relationships</b>	Independent with no difficulties	His parents and ex-wife are becoming increasingly frustrated at his lack of progress with recovery. While Jarrod feels bad about relying on them for so much, he also feels angry because he feels they don't understand how much difficulty he has with daily life.
<b>Friendships</b>	Independent with no difficulties	Lost a lot of social contacts he previously had via his children's school. Regular contact with a friend from Park Run, football club and neighbour. However, Jarrod doesn't feel like he contributes much to these friendships.

## Jarrod's Goals

Jarrod is able to identify a couple of areas where his health has improved, but overall, he feels that his life is on pause, and he is not sure how to move forward. He wants to work with people who know about Long COVID and acknowledge the massive changes it has brought to his life. Jarrod is focused on returning to work because this will solve his financial problems and, in his words, 'give me back some of my dignity'.

His goals (in no particular order) are to:

- Return to work as a painter and decorator or in a related job.
- Feel less pain and stiffness in his body.
- Get back to completing all his activities for himself and no longer rely on others.

- Spend more time with his kids, including looking after them on his own.
- Get back into regularly riding, running and hiking to reconnect with nature.

## What Does The Evidence Say?

### **Musculoskeletal pain as a symptom of Long COVID**

- Musculoskeletal pain is one of the most common symptoms of Long COVID but is highlighted less often than symptoms like fatigue and brain fog in the literature<sup>1</sup>.
- The prevalence of these symptoms has been identified as 45% – 60% reported musculoskeletal pain as a persistent symptom after hospital discharge<sup>2 3</sup>. People with mild, moderate and

1. Khoja, O., Silva Passadouro, B., Mulvey, M., Delis, I., Astill, S., Tan, A. L., & Sivan, M. (2022). Clinical characteristics and mechanisms of musculoskeletal pain in long COVID. *Journal of Pain Research*, 1729-1748.
2. Ali, M., & Bonna, A. S.. (2022, January 1). Is Coronavirus Infection Associated With Musculoskeletal Health Complaints? Results From a Comprehensive Case-Control Study. *Journal of Primary Care & Community Health*, 13, 215013192211142. <https://doi.org/10.1177/21501319221114259>

severe initial symptoms have reported this symptom.

- Musculoskeletal pain for people with Long COVID may arise from myositis, neuropathy, arthropathy, and soft tissue abnormalities<sup>4</sup>. Emotional and social factors, including anxiety, depression, and poor sleep quality, may also play a role in the development of musculoskeletal pain following COVID-19 infection<sup>5</sup>.

### **Vocational rehabilitation for Long COVID**

- A growing body of evidence suggests vocational rehabilitation may be an effective intervention for people experiencing Long COVID to counter the significant impact of the syndrome

3. Garg, M., Maralakunte, M., Garg, S., Dhooria, S., Sehgal, I., Bhalla, A. S., ... & Sandhu, M. S. (2021). The conundrum of 'long-COVID-19: a narrative review. *International journal of general medicine*, 2491-2506.
4. Ramani, S. L., Samet, J., Franz, C. K., Hsieh, C., Nguyen, C. V., Horbinski, C., & Deshmukh, S. (2021). Musculoskeletal involvement of COVID-19: review of imaging. *Skeletal Radiology*, 50, 1763-1773.
5. Fernández-de-Las-Peñas, C., Cancela-Cilleruelo, I., Moro-López-Menchero, P., Rodríguez-Jiménez, J., Gómez-Mayordomo, V., Torres-Macho, J., ... & Arendt-Nielsen, L. (2022). Prevalence of Musculoskeletal Post-COVID Pain in Hospitalized COVID-19 Survivors Depending on Infection with the Historical, Alpha or Delta SARS-CoV-2 Variant. *Biomedicines*, 10(8), 1951.

- on financial resources and quality of life <sup>6</sup>.
- A study with 81 participants found workers undergoing Long COVID rehabilitation experienced significant but modest improvements in various outcomes (including pain). However, only 53% returned to work <sup>7</sup>.
- A detailed and individualized return-to-work plan should be developed to guide modifications to working conditions (like workload adjustments, adjusted working hours or redesigned tasks) <sup>8</sup>.
- Published guidance recommends employers provide flexible working arrangements and support for employees with Long COVID and that a gradual return to work supported by individualized adjustments be implemented <sup>9</sup>.

6. Cutler, D. M. (2022, May). The costs of long COVID. In JAMA Health Forum (Vol. 3, No. 5, pp. e221809-e221809). American Medical Association.
7. Brehon, K., Niemeläinen, R., Hall, M., Bostick, G. P., Brown, C. A., Wieler, M., & Gross, D. P. (2022). Return-to-work following occupational rehabilitation for long COVID: Descriptive cohort study. *JMIR Rehabilitation and Assistive Technologies*, 9(3), e39883.
8. Müller, K., Poppele, I., Ottiger, M., Zwingmann, K., Berger, I., Thomas, A., Wastlhuber, A., Ortwein, F., Schultz, A., Weghofer, A., Wilhelm, E.M., Weber, R., Meder, S., Stegbauer, M., & Schlesinger, T. (2023). Impact of Rehabilitation on Physical and Neuropsychological Health of Patients Who Acquired COVID-19 in the Workplace. *International Journal of Environmental Research and Public Health*, 20.



## Exercise and recreation for people with Long COVID

- It is important to note that some people with Long COVID experience significant relapses in their symptoms following exertion. Therefore, it may not be appropriate or safe for everyone to engage in physical activity. A thorough assessment and supervision by a healthcare professional is recommended before beginning any exercise program.
- Guidance is available for exercise prescriptions for people with Long COVID, which recommends a gradual and individualized approach that starts with low-intensity exercise (such as walking or cycling), and gradually increases duration and intensity over time<sup>10</sup>.
- While there is no specific evidence around the use of nature and parks by people with Long COVID, several studies have investigated the health impacts of green spaces during the COVID-19 pandemic. Public health measures prompted an increase in outdoor recreational

9. National Institute for Health and Care Excellence. (2021). COVID-19 rapid guideline: managing the long-term effects of COVID-19. December 2020. Available from <https://www.nice.org.uk/guidance/ng188>

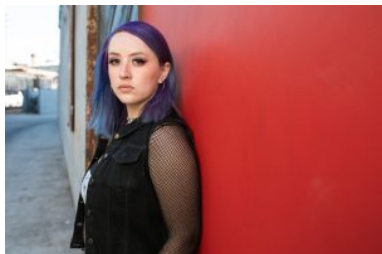
10. American College of Sports Medicine. (2021). ACSM call to action statement: COVID-19 considerations for sports and physical activity. Available from [https://www.acsm.org/read-research/resource-library/resource\\_detail?id=ec62b5c5-5fe5-4e5d-b2d2-bbd8f6432eac](https://www.acsm.org/read-research/resource-library/resource_detail?id=ec62b5c5-5fe5-4e5d-b2d2-bbd8f6432eac)

activities for the general public as a way of facilitating social distancing<sup>11</sup>. Exposure to nature (even via a view out a window) was also found to decrease depression and anxiety in the general public during the pandemic<sup>12</sup>. A systematic review from before the pandemic also found exercise in natural environments is associated with greater feelings of revitalization and positive engagement<sup>13</sup>.

11. Venter, Z. S., Barton, D. N., Gundersen, V., Figari, H., & Nowell, M. (2020). Urban nature in a time of crisis: Recreational use of green space increases during the COVID-19 outbreak in Oslo, Norway. *Environmental research letters*, 15(10), 104075.
12. Soga, M., Evans, M. J., Tsuchiya, K., & Fukano, Y. (2021). A room with a green view: the importance of nearby nature for mental health during the COVID-19 pandemic. *Ecological Applications*, 31(2), e2248.
13. Thompson Coon, J., Boddy, K., Stein, K., Whear, R., Barton, J., & Depledge, M. H. (2011). Does participating in physical activity in outdoor natural environments have a greater effect on physical and mental wellbeing than physical activity indoors? A systematic review. *Environmental science & technology*, 45(5), 1761-1772.

# 8. Jennifer Knowles

*By Emily Rawlings & Danielle Hitch*



**Jen Knowles.** Photo by [RODNAE Productions](#) from [Pexels](#).

Jennifer (Jen to her friends) is a 26-year old Anglo-Australian woman who recently moved to Geelong from inner city Melbourne to attend university. She is a keen fan of alternative music and considers herself a quirky, artistic, and creative person. Jen also enjoys

fashion and particularly loves the work of Vivienne Westwood. Her friends describe her as a strong and independent woman who is open to new experiences and willingly jumps at every opportunity that comes her way.

## Home Life

Jen and her older brother (Sam) grew up with their father (Robert) in an expansive inner city terrace house. Her mother (Vanessa) left their home when Jen was five and remarried a new partner. Vanessa lives in Melbourne with her three younger children, but Jen has a limited relationship with her mum and rarely sees her half-siblings. In contrast, she has a close and warm relationship with her father and brother and gets along well with her sister-in-law (Kelsey). Sam and Kelsey have five-year old twins (Stella and Augie) and a three-year old daughter (Neve), who Jen often babysits. She often catches the

train up to Melbourne to be with her family, and they visit her at least once a month.

Jen has been in a new relationship for the past two years with Johan (known as Jo), who she met at an art exhibition. He is ten years older than Jen and immigrated to Australia as a young child from South Africa. Jo works as a lighting technician and spends his days completing hard physical work. As a result, he has acquired chronic lower back pain, sometimes preventing him from working. Jo has also experienced bouts of depression since his teenage



**Johan at work.** Photo by [Kyle Loftus](#) from [Pexels](#).

years, for which he takes anti-depressants. They enjoy a close and loving relationship and have spoken of the possibility of getting married in the future. Jen and Jo share ownership of a one-year old Maltese terrier called Miro.

***“We nerd out about music, comics, and art – we just get each other”.***

Jen works two casual jobs to support herself and Jo while studying. She works casual shifts at the local hospital as a food services assistant, helping to prepare and deliver patients' meals. This job fits in around her university lectures and seminars, and she chooses work over university whenever provided the option to watch lectures or seminar recordings in lieu of attendance. Jen also works casually in hospitality as a waitress at a local convention centre, which gives her shifts most Friday and Saturday nights.

**“I’d rather be at uni because I love it, but I’ve got rent to pay”**

## Community



***Jen and Johan often visit the river.*** [Marcus Wong Wongm, CC BY-SA 4.0](#) via [Wikimedia Commons](#)

Jen and Ben moved to Geelong one year ago after she was accepted into the Bachelor of Design course. They enjoy the slower pace of the city, easy access to the beach and its vibrant arts and cultural scene. They live in an outer suburb and have all the essential amenities (like a supermarket, chemist, and

medical centre) within walking distance of their townhouse. There are also numerous green spaces along the river in the local area, where Jen likes to walk Miro and jog two to three days per week. She also attends local markets but doesn't know her way around the broader city very well. Jen also finds it difficult to interact with new people, as she tends to be shy with those she doesn't know well.

However, Jen and Ben have struggled to build a relationship within their new community, as their arrival coincided with pandemic public health restrictions. They are acquainted with one neighbour, as Jen has spoken to her several times as their dogs were socializing with each other. Jen has some workmates she keeps in contact with but does not know them particularly well. Ben has never had a wide social network, as his job rarely sees him working with the same group of people for any length of time. Their financial position also constrains their ability to participate in community activities, as both are on relatively low incomes.

*"It's peaceful down here, but it doesn't feel like home yet."*

## Health

Jen doesn't have any pre-existing illnesses or disabilities. She had dental surgery at 16 to manage painful wisdom teeth but has required no other procedures and is not on any medication currently. Jen and Jo are vegetarians and try to cook from fresh ingredients



***Lots of people tested COVID positive at the same time.*** Photo by [Alex Koch](#) from [Pexels](#).

wherever possible. She does not have a regular general practitioner (GP) and sees whoever is available on the rare occasions she visits the local medical centre.

## COVID-19

### ***Acute Infection***

Jen contracted COVID-19 at the end of June 2022 and believes this was acquired at her hospital job. She had been doing extended hours and additional days due to workforce shortages and wonders if her general sense of being 'run down' at the time made her more susceptible. It had also been ten months since her last vaccination dose, and she was trying to make time for her next booster when she became infected.

Jen began to feel increasingly unwell the day after she tested positive on a Rapid Antigen Test (RAT) offered at the hospital after a ward outbreak. She and Jo agreed that he should stay

with friends in Melbourne to minimize his chances of getting sick and missing out on work. Jen informed her university lecturers that she would not be attending on-site for at least seven days, and they reassured her that she could keep up with her work remotely.

***“I didn’t want to be alone, but I thought that was the right thing to do.”***

Along with a sore throat, cough and runny nose, she felt profoundly fatigued and slept for most of the following three days. When awake, she felt so drowsy that she would forget what she was doing when moving around the house and could not concentrate on the simplest tasks for longer than one or two minutes. Jen also experienced gastrointestinal symptoms, including nausea, cramping and diarrhea on most days. Embarrassingly, she also began to experience urinary incontinence, particularly when experiencing coughing fits.

From day six onwards, Jen started to feel more energized but still experienced persistent lethargy and post-exertional malaise. She wasn’t eating much or completing self-care tasks because it felt like too much effort. Her cough improved slightly, but it still troubled her overnight (disturbing her sleep) and after any form of physical activity. Jen lost five kilograms over the first two weeks of her COVID-19 infection.

As time wore on, Jen started to feel her energy levels lift, but they were still far lower than normal. While she had been very aware of her physical fatigue initially, she now became increasingly aware of the effect of fatigue on her attention and thinking as the demands on her increased. Jen likened it to *‘a hangover that just doesn’t quit’* and felt frustrated by how long simple tasks took her. Her sore throat and running nose completely resolved after a week; however, her cough stubbornly held on. While she was now able to return to work and university, Jen felt very self-conscious about coughing but was unable to suppress it. Jen also continued to experience

gastrointestinal upsets (although less frequently) and urinary incontinence daily.

***“Now I get what they mean by ‘brain fog’. I just can’t keep my mind on anything.”***

## ***Developing Long COVID***



***The GP suggested a mindfulness app.*** Photo by [Marek Levak](#) from [Pexels](#).

After a month of ongoing symptoms, Jen realized she wasn't recovering from COVID-19 as quickly and easily as her friends. She saw the same GP on three consecutive visits and asked for help to relieve her cough and feel less fatigued. However, Jen was left feeling

that the doctor didn't take her symptoms seriously, and by the third visit, she could see he thought she was a nuisance. She felt that she needed to justify her requests for tests or treatment and came to that appointment with some information from the internet about cough remedies to seek his advice. He laughed and said, *“If you think Dr Google knows more than I do then why are you here?”*. The GP then suggested she download a mindfulness app and consider visiting student services at the university to get mental health help. Jen felt discouraged and helpless, as there seemed to be no support or services available to help.

While she had returned to her work and university course, Jen was struggling to keep up with all her duties. She tried to manage her fatigue by avoiding social or leisure activities to focus only on what she 'had' to do. Jen also started to avoid activities in the community, as she was very scared of not getting to the toilet in time. She often napped to recharge in



between activities but struggled to get any restful sleep. Jen reduced her shifts at the convention centre because that job involved long periods of standing and carrying items. However, her boss told her, *"We can't hold a place for you if you aren't reliably available"*, and shift offers soon dried up. This was the higher paid of her two jobs, and the loss of this work had a big impact on her finances. Jen continued to work at the hospital and took extra shifts there when she could. Her boss and co-workers were more understanding; they knew colleagues who had also had a long road to recovery after COVID-19 infection.

Jen was also increasingly struggling with the demands of her university course. Her marks deteriorated, and she particularly struggled with group assignments that required negotiation with other students. While she still loved her course, being with everyone on campus reminded her how much she missed out. Jen tried to keep up with weekly coursework but found reading materials online more difficult than in hard copy. However, she couldn't afford to print everything out and continued struggling. Coincidentally, Jo was experiencing an episode of depression, and while they were spending more time than ever together, they went entire days without really speaking with each other.

***“I can only do one thing at a time. I read the same paragraph over and over again”.***

Jen tried again to get support from a different GP and asked whether she might have Long COVID. The doctor told her that she didn't really know much about the condition, and it wasn't clear whether it was a real condition or just the stress everyone had been under during the pandemic. Jen had heard of the Royal Melbourne ReCov Program and asked if the GP would refer her there. However, the

doctor dissuaded her, saying, *“Their waiting list is massive, and honestly, that clinic is for people with far worse symptoms than you”*. No other services or support were mentioned or offered, so Jen gave up on getting help from mainstream medicine and began to look at alternatives. She still experienced daily bloating, cramping and flatulence and self-diagnosed herself with irritable bowel syndrome. Jen has tried some dietary changes and natural remedies (such as peppermint from her garden), but neither made much difference. After her initial weight loss during the acute phase of her COVID-19 infection, she has now gained approximately ten kilograms from her original weight and feels increasingly uncomfortable in her body.

Jo tries to be helpful, but the amount of support he can offer depends on the state of his own health problems. Her father visited her recently and was shocked at how unwell she looked.



***Jen tried peppermint to ease her gut symptoms.*** Photo by [Karolina Grabowska](#) from [Pexels](#).

He has been looking for treatment options in Melbourne but is coming up against similar barriers to knowledge and access. However, Sam has been visiting Geelong regularly to help her and Jo with household tasks. She has become closer to Kelsey during regular supporting phone conversations with them. While part of her is relieved she has not been asked to look after her nieces and nephew recently, Jen is aware this makes things difficult for her brother and sister-in-law and feels very guilty about letting them down.

***“I can’t wait to be Auntie Jen Jen again, but I’m not ‘with it’ enough now to care for them properly”.***

## Current Situation



***Thi always makes her laugh, but her visits wear Jen out.*** Photo by [RODNAE Productions](#) from [Pexels](#).

Jen has developed some strategies for managing her fatigue and brain fog a little better, but it still has a significant impact on her life. Her gut problems now feel under control, and her incontinence has improved somewhat. Her cough is also less evident, but she still

experiences a coughing fit at least once a week, always accompanied by urinary incontinence. Jen still needs to nap most days and no longer does most domestic chores at home. Jen has worked hard to be more forgiving of herself and feels that she now needs to accept that she is no longer quite the girl she was before COVID-19. Her mindset swings between making the most of what she can do and profound frustration with all the things she cannot do.

Jen keeps abreast of developments in the field of Long COVID, primarily through online peer support groups run by

other people with this syndrome. However, she finds these groups very stressful because many members are older than her, and they focus almost completely on the negatives of their situations. Thi still visits monthly and is accommodating and supportive, but Jen sometimes finds her extroverted and chatty friend exhausting. Recently, she has begun to wonder if it would be worth revisiting a GP and seeking a referral to a specialist.

***“I just want to feel my age ... maybe now they've had time to sort out how to treat it”.***

## **Life Roles**

Jen feels she has struggled with maintaining her life roles, and her participation in most of them has changed considerably.

Role	Before COVID-19	Currently
Student	Full-time university student, completing a Bachelor of Design course primarily on campus.	She is a full-time student but now completes most of her classes online. She barely passes and is considering reducing her load for the next Trimester.
Home Maintainer	Took responsibility for all household tasks, including housework, dishes, cooking, laundry, and maintaining the veggie garden and pot plants. Jo assisted as and when his back pain allowed.	Jo is now responsible for all these tasks; however, he is not always able to complete them. Jen helps when she can, but her ability varies daily.
Worker	A casual employee at a hospital job (approximately 24 hours a week) and a convention centre (approximately 16 hours per week).	No longer working at the convention centre. Picks up extra shifts at the hospital, when possible, where she is now working 24-32 hours a week).
Friend	Regular phone contact with two old friends (Ruby and Thi) from Melbourne. Thi also visited her in Geelong every couple of months. Limited contact with other friends, most of which is online via social media.	Social engagement has reduced since being with Jo, as she spent more time at home with him, and they would rarely go to community events together. There have been few opportunities to make new friends in Geelong, and the opportunity to do this at university has been curtailed due to Long COVID symptoms. Jen often feels isolated and lonely.
Family Member (child, partner, parent or other relation)	Partner, daughter, sister, sister-in-law and aunty. Jen belongs to a close and supportive family, who are frequently in contact.	Jen's family remains her primary source of support, consistently validating her symptoms and offering as much help as possible. They are increasingly worried about her health and well-being.

Neighbour	<p>Acquainted with one neighbour (Jeremy) who lives with his elderly mother (Betty) and their dog (Tiny) next door. Jen spoke with him socially several times a month when their paths crossed while dog walking. Jen and Jo don't know their other neighbours.</p> <p>Jen hasn't seen Jeremy since she caught COVID-19, as she has not been walking Miro. A bunch of flowers subsequently appeared on their doorstep, with a note saying he and Ethel were thinking of her and would come dog walking with her if that would help.</p>
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## Activities of Daily Living



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=365#h5p-8>

**Miro.** Photo by [Migs Reyes](#) from [Pexels](#). / **Hospital Food.** [BrokenSphere, CC BY-SA 4.0](#) via [Wikimedia Commons](#) / **University Lecture Hall.** Photo by [Pixabay](#) from [Pexels](#).

Jen's participation in daily life has also diminished since her COVID-19 infection, and she feels she is living a 'lesser life' now.

Activity	Before COVID-19	Currently
Showing / Bathing	Independent. The townhouse has a shower only.	Able to complete independently, the task takes longer, and Jen often needs a short rest afterwards. Keeping her hands and arms up when washing her hair is particularly tiring.
Toileting	Independent and fully continent.	More frequent and longer toileting for both urine and bowel motions. Has maintained bowel continence but still experiences periodic stress incontinence when coughing. Also troubled by frequent bouts of incontinence and cramps, which do not appear to be related to diet.
Dressing	Independent. Interested in fashion and makes an effort to be well-dressed daily.	Able to complete independently, but no longer motivated to be fashionable. Minimal effort is expended on clothing, and she often wears baggy leisure garments. Her weight gain means many of her fashionable clothes no longer fit her.
Eating	Independent. Vegetarian and eating a good selection of fresh, non-processed food.	Able to complete independently, but diet is no longer as balanced or healthy. Often resorts to ready meals or simple food (i.e., toast) as she does not have the energy to cook. Inconsistent mealtimes, primarily consisting of snacking around naps, work and study.
Walking / Moving around	Independent and able to mobilise for as long as she wished.	Reduced exercise tolerance and comfortably managing short (10-15 minute) walks. She is far more sedentary in her daily life, as she often stays in bed or sits on the couch most of her time at home. No longer attending the university campus regularly or delivering meals to the wards at the hospital.

Personal Hygiene / Grooming	Independent and maintained to a high standard. Hair was washed and styled daily. Mouth hygiene was completed, and make-up was applied daily.	Less frequently hair washing and brushing and keeps her hair in plaits for days at a time. Brushes her teeth every second day and rarely wears make-up. Shaving is particularly difficult as she finds bending and reaching particularly tiring.
Sexual Activity / Intimate Relationships	In a loving relationship with Jo, including regular intimacy.	Reports her libido is reduced and less consistent. Feels a lack of connection with Jo at times, particularly when they are both struggling with their health and well-being. Jen and Jo both feel their relationship has been 'cooler' since Jen got COVID-19, but they remain committed to each other.
Caring for others	Carer for Jo during his bouts of depression and chronic back pain. Regularly babysits her nieces and nephew (Stella, Augie, Neve) in Melbourne and Geelong. Occasionally supports her father (Robert) as he begins to age.	Reduced capacity for caring responsibilities due to both fatigue and brain fog. Jo has taken on many caring tasks for her, supplemented by her brother Sam. She worries that she could place the children in danger as she isn't alert enough. Jen particularly values caring tasks and feels her loss of ability in this area very keenly.
Pet / Animal Care	Walked Miro for up to an hour every day and twice a day if the weather was pleasant.	Limited to short walks with Miro and cannot do this on some days. Jo now undertakes most feeding duties, and grooming has lapsed.



Communication with others	Independent. Able to communicate with a wide range of people in diverse circumstances.	She has difficulty clearly communicating her thoughts and providing clear and relevant responses. Due to her brain fog, she finds spoken communication overwhelming at times and doesn't remember everything she has been told. Jen now prefers online / written communication because it gives her more time to compose her thoughts, and she can refer to what people have said.
Driving / Public Transport	Able to drive but doesn't own a car. Independent and frequent user of public transport.	Reduced focus and concentration led to a lack of self-confidence in driving, which she now avoids (particularly at nighttime). This makes her dependent on Jo for any trip which can't be completed by public transport. Able to take trains and buses but feels anxious about being in a closed space with many people due to the risk of re-infection. She is also increasingly finding it difficult to afford the fares.
Money management / Budgeting	Jen and Jo combined their income for bills and utilities while maintaining separate bank accounts. Jen prided herself on being good with money and was able to live within her limited means.	Jens reduced working hours have resulted in the couple budgeting more strictly. They are unable to participate in some of the activities they previously enjoyed. While they are under mortgage and bill stress, they are not in arrears or in danger of legal action. Jen worries about the future, however, particularly as the cost of living rises.

Home Maintenance	Jo undertook most maintenance activities. However, Jen could also independently complete simple repair and maintenance jobs when required.	Jen finds the simple jobs she previously took care of (i.e., lawn mowing and minor repairs) very taxing and tiring. With Jo's own health problems, these tasks are not being completed regularly. Both find it particularly hard to participate when the weather is cold or wet.
Meal Preparation	Independent and shared tasks with Jo.	Jen feels horrible about her current performance of this task. She can prepare relatively simple meals but leaves the clearing up to Jo (who is not always able to do it). She has tried to prepare more complex meals she previously enjoyed, but her attempts have not been successful.
Shopping	Jen and Jo shared these tasks and were able to perform them independently.	She often shops online and purchases smaller orders as she cannot plan a full weekly menu. Convenience and food prices dictate purchases, leading to an increase in processed and 'ready' meals. Neither Jen nor Jo has a discretionary budget for non-essential shopping.
Taking care of health	Independent.	Jen had disengaged from her GP due to dissatisfaction with their management of her Long COVID. She has not seen other health providers, primarily because she cannot afford their fees.

Rest/Sleep	Regular sleep schedule and no issues with insomnia or other sleep problems.	Jen's sleep requirements and her need to rest and take short breaks during the day have increased dramatically. However, her sleep feels less restful, and she often wakes up tired. Jen finds it very difficult to wake up and cannot be easily roused by environmental noises. For example, she won't fully wake even when Miro barks loudly on her bed.
Education	Motivated and well-engaged student.	Jen is finding it increasingly difficult to follow instructions with multiple steps. It also seems more time-consuming to understand new ideas, and Jen often struggles to summarise new information. She must return to readings multiple times, as her attention often wanders from what is in front of her.
Work (Paid or Voluntary)	Casual jobs as a food services assistant and waitress. Reliable and valued employee.	She no longer works as a waitress but has retained food services job. Jen avoids social conversations at breaks in preference to spending time alone to 'recharge'. She needs more breaks and is not working at her usual speed. Supportive hospital employers and colleagues who are familiar with Long COVID.
Play / Leisure	Favourite hobbies were gardening, crafting and sewing. Jen was considering returning to her childhood sport of tennis to meet more people locally. Jen was also an avid reader of fantasy fiction.	Jen has given up on her goal of playing tennis. She pushes herself to do light gardening several times a week but is becoming discouraged by how neglected her garden now looks. Jen hasn't been crafting or sewing, as she runs out of energy to pack away her equipment and materials, contributing to messiness and clutter at home.

Friendships	Regular phone contact with two old friends. Occasional face-to-face contact with one of these friends, but most social connections are online.	She no longer speaks to Ruby by phone, as Jen felt she was not empathetic to her struggles. Thi still calls and visits and has been trying to support Jen to increase her activities slowly. Online communication is now Jen's preferred format, but she is more selective in who she contacts.
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***"It's so weird having people help me with stuff. I'm not too proud to ask for help .... but I should be the one looking after others."***

## **Jen's Goals (*in no particular order*)**

1. To get over my fatigue and demotivation, so I can do the household activities I used to do
2. To no longer have toilet problems
3. To improve my performance at university
4. To pick up more hours at the hospital or by taking on a new job
5. To get out and about more in my local community

***"I'm young; I was fit, so I think I can get better. But I need help from people who really get Long COVID."***

## What does the evidence say?

There is a general perception that Long COVID predominantly affects middle-aged people, and research into its impact on younger adults is not extensive.

**Young people with Long COVID may not be receiving the care they need.**

- Walsh-Messinger et al.<sup>1</sup> found around a third of tertiary students with Long COVID in the United States had no contact with healthcare providers despite experiencing significant symptoms. They suggest that student health services should closely monitor the recovery of all young people following COVID-19 infection. However, colleges and universities are yet to develop resources and support for students with Long COVID<sup>2</sup>, and

1. Walsh-Messinger, J., Manis, H., Vrabec, A., Sizemore, J., Bishof, K., Debidda, M., Malaspina, D., & Greenspan, N. (2021). The kids are not alright: A preliminary report of Post-COVID syndrome in university students. *Journal of American College Health*, Online First. doi: 10.1080/07448481.2021.1927053.
2. Vance, L., & Aquino, K. (2023). Dealing with the impact of Long COVID on college campuses. *Disability Compliance in Higher*

knowledge of the syndrome among health professions remains variable <sup>3</sup>.

- While young people are more likely to experience mild symptoms during their COVID-19 infection, evidence shows this can still lead to persistent cognitive and mental health deficits <sup>4</sup>. There are immense barriers to accessing youth mental health services for many young Australians, with around half of this group not receiving the care their need <sup>5</sup>.

### **Less common symptoms**

- People whose symptoms profile differs from

Education, 28(7), 6-7.

3. Baz, S., Fang, C., Carpentieri, J., & Sheard, L. (2023). 'I don't know what to do or where to go'. Experiences of accessing healthcare support from the perspectives of people living with Long COVID and healthcare professionals: A qualitative study in Bradford, UK. *Health Expectations*, 26(1), 542-554. doi: 10.1111/hex.13687.
4. Manukyan, P., Deviatierikova, A., Velichkovsky, B., & Kasatkin, V. (2022). The impact of mild COVID-19 on executive functioning and mental health outcomes in young adults. *Healthcare*, 10, 1891. doi: 10.3390/healthcare10101891.
5. Savaglio, M., O'Donnell, R., Hatzikiriakidis, K., Vicary, D., & Skouteris, H. (2022). The Impact of Community Mental Health Programs for Australian Youth: A Systematic Review. *Clinical Child & Family Psychology Review*, 25(3), 573–590. doi: 10.1007/s10567-022-00384-6

the 'classic' post-viral picture of brain fog and fatigue may struggle to access Long COVID specific clinics, which are generally led by respiratory or neurology specialists.

- Abdominal pain and diarrhea are reported by approximately 14% and 10% of people recovering from COVID respectively <sup>6</sup>. The virus is known to disrupt gut microbiota, leading some to propose using pre or pro-biotics as part of Long COVID treatment <sup>7</sup>. However, the roles of gastroenterology and nutrition/dietetics in managing Long COVID remain in their infancy.
- Issues with bladder control are reported by up to 14% of people recovering from Long COVID <sup>8</sup>

6. Choudhury, A., Tariq, R., Jena, A., Vesely, E. K., Singh, S., Khanna, S., & Sharma, V. (2022). Gastrointestinal manifestations of long COVID: A systematic review and meta-analysis. *Therapeutic Advances in Gastroenterology*, 15, 17562848221118403. doi: 10.1177/17562848221118403
7. Alharbi, K. S., Singh, Y., Hassan almalki, W., Rawat, S., Afzal, O., Alfawaz Altamimi, A. S., Kazmi, I., Al-Abbasi, F. A., Alzarea, S. I., Singh, S. K., Bhatt, S., Chellappan, D. K., Dua, K., & Gupta, G. (2022). Gut Microbiota Disruption in COVID-19 or Post-COVID Illness Association with severity biomarkers: A Possible Role of Pre / Pro-biotics in manipulating microflora. *Chemico-Biological Interactions*, 358. <https://doi.org/10.1016/j.cbi.2022.109898>
8. Davis, H., Assaf, G., McCorkell, L., Wei, H., Low, R., Re'em, Y..... & Akrami, A. (2021). Characterizing long COVID in an international cohort: 7 months of symptoms and their impact.

and can affect people of any age. COVID19 associated cystitis (presenting as overactive bladder) is also been reported <sup>9</sup>, although the current evidence focuses on middle age or older people.

- Decreased libido is associated with one of the highest adjusted hazard ratios (2.36) in long COVID <sup>10</sup>, although none of the existing studies focuses specifically on female sexuality.

### **Impact of Long COVID on education and training activities**

- While young adults are not often the target sample of Long COVID studies, findings from some studies indicate they may experience increased depression and disinhibition <sup>11</sup>, balance

eClinical Medicine, 38, 101019. Doi:10.1016/j.eclinm.2021.101019.

9. Lamb, L. E., Timar, R., Wills, M., Sorabh, D., Lucas, S. M., Dragana, K., . . . Nivedita, D. (2022). Long COVID and COVID-19-associated cystitis (CAC). *International Urology and Nephrology*, 54(1), 17-21. doi: 10.1007/s11255-021-03030-2
10. Subramanian, A., Nirantharakumar, K., Hughes, S. et al. (2022). Symptoms and risk factors for long COVID in non-hospitalized adults. *Nature Medicine*, 28, 1706–1714. doi: 10.1038/s41591-022-01909-w
11. Manukyan, P., Deviaterekova, A., Velichkovsky, B. B., & Kasatkin, V. (2022). The Impact of Mild COVID-19 on Executive Functioning and Mental Health Outcomes in Young Adults. *Healthcare* (2227-9032), 10(10), N.PAG. doi:10.3390/healthcare10101891



problems<sup>12</sup>, and reduced<sup>13</sup>.

- However, a study from Sweden<sup>14</sup> indicates that university students with a history of COVID-19 infection do not experience any significant cognitive problems when completing neurocognitive tests in comparison to their non-infected peers. There is also some evidence that autonomic function and physical activities do return to baseline over time for this cohort of patients<sup>15</sup>.

12. Guzik, A., Wolan-Nieroda, A., Kochman, M., Perenc, L., & Drużbicki, M. (2022). Impact of mild COVID-19 on balance function in young adults, a prospective observational study. *Scientific Reports*, 12(1):1-8. doi:10.1038/s41598-022-16397-8
13. Walsh-Messinger, J., Manis, H., Vrabec, A., Sizemore, J., Bishof, K., Debidia, M., Malaspina, D., & Greenspan, N. (2021). The kids are not alright: A preliminary report of Post-COVID syndrome in university students. *Journal of American College Health*, Online First. doi: 10.1080/07448481.2021.1927053.
14. Francis, G., & Thunell, E. (2023). COVID-19 infection does not seem to affect cognition in college students. *Consciousness and Cognition*, 108, 103464. Doi: 10.1016/j.concog.2023.103464.
15. Freire, A. P. C. F., Amin, S., Lira, F. S., Morano, A. E. von A., Pereira, T., Coelho-E-Silva, M.-J., Caseiro, A., Christofaro, D. G. D., Dos Santos, V. R., Júnior, O. M., Pinho, R. A., & Silva, B. S. de A. (2023). Autonomic Function Recovery and Physical Activity Levels in Post-COVID-19 Young Adults after Immunization: An Observational Follow-Up Case-Control Study. *International Journal of Environmental Research & Public Health*, 20(3), 2251.

## References

<https://doi.org/10.3390/ijerph20032251>.

## 9. Joshua Leggatt

*by Wendy Hocking &  
Danielle Hitch*

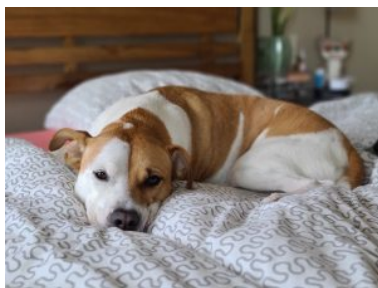
Joshua (known to his friends as Josh) is a 35 year old man whose family have lived in Australia for many generations. He works as an office assistant in a local



**Josh Leggatt.** Photo by [MART Productions](#) from [Pexels](#).

business, where he has been employed for approximately ten years. Josh is a keen Collingwood Football Club supporter and enjoys attending local football league games during the winter. He is currently single but was previously in a long-term relationship. Josh is a friendly and fun-loving man who loves to chat with his friends and co-workers and has a great sense of humour.

### *Home Life*



**Chumpy.** Photo by [Viktoria B.](#) by [Pexels](#).

Joshua lives with his parents (Bob, 82 and Jane, 80) in a rented property on the outskirts of a large regional town. His parents are both on an aged pension, so the family has limited income. They have lived in their rental property for over a decade, over which time the rent has increased

significantly. The family now has little disposable income and limited means to participate in community activities. Their landlord does not respond to requests for repairs or maintenance on the property, which is now somewhat dilapidated. The home environment is also very messy and cluttered, as all three residents struggle with the physical and motivational demands of housework.

Josh has two brothers who live in the local area (Tom, aged 39 and Leo, aged 43). The current state of their home discourages his brothers from visiting as regularly as they used to. Josh also had a sister (Sarah) who died in a car accident when he was ten years old. Jane was driving Sarah back from dance practice at the time and subsequently developed significant depression and alcohol dependence following the accident. Bob became Jane's primary carer while working full-time until he turned 70 years old. Josh has a dog called Chumpy, with whom he spends most of his time at home.

***“Chumpy is my best mate .... he looks after me, and I look after him.”***

## Community

Joshua lives in a town called Bendigo, which has around 120,000 people. The town is a regional hub surrounded by farming communities and has many sporting clubs, educational institutions, cultural facilities and green spaces. The town is linked to other major population centres by train,



**Central Bendigo.** Photo by [Michael Coghlan](#), [CC BY-SA 2.0](#), via Wikimedia Commons

and there are also local public bus services (although they tend to be infrequent in Josh's local area).

Along with his immediate family, Josh has five extended family members living in Bendigo or surrounding towns. He sees them occasionally, but they are not a regular presence in this life. He completed all of his schooling in Bendigo and used to attend a hub called [Creative Links](#), which supports people with disability to link with and participate in community activities. He stopped attending when he broke up with his former partner, a client of this service. However, he is familiar with many of the local facilities and groups from his time there. The town is very pretty, with historic buildings that bring many tourists.

***“I like the big lake ... especially when its sunny. There's lots of ducks”***

## *Health*

Joshua was born with Down Syndrome, which is a genetic disorder that causes developmental and intellectual delays. His condition was identified at birth, and he was delayed in meeting developmental milestones throughout his childhood. Joshua received support from a teacher's aide and a support worker throughout his education while completing his office administration traineeship at his current job. However, he is not receiving any additional disability support currently.

His parents know that Josh could receive assistance under the National Disability Insurance Scheme but have felt overwhelmed by their two attempts to complete their Access Request Form. As stated by Bob, *“They just keep asking for more and more information, and we don't have any updated assessments because ... well, Josh is just Josh. They say he's got special needs, but to be honest he just needs the same as everyone else”*.

For more information about the health and well-being aspects of Down Syndrome, please watch this [webinar from Down Syndrome Queensland](#).

His family have always encouraged him to participate in life to the fullest possible degree and actively advocate for Josh whenever necessary. Before the COVID-19 pandemic, he experienced periods of feeling sad and anxious, which interfered with his daily life. His general practitioner (Dr O'Reilly) diagnosed Josh with depression, and he continues to take an anti-depressant to help with these symptoms. His current body mass index is 29 (overweight), but he has no other significant health issues. He wears glasses for all activities and has done since early childhood. Dr O'Reilly has known him since childhood and has a great rapport with him and his parents.

***"I HATE exercise .... I get tired, and its SO boring."***

## COVID-19

### Acute Infection

Josh believes he got COVID-19 at work, but he's unsure because many other people had it at the time. He enjoys having lunch in the staff room and talking to everyone, and someone in the room was coughing a lot. After that, many people at work got sick, and the business had to shut down for a few days due to a lack of staff. His employer arranged for everyone to do a rapid antigen test, and that's how he found out he had COVID-19.

***"I was OK, but then I got sick."***



**Dr O'Reilly – Joshua's GP.** Photo by [RODNAE Productions](#) by [Pexels](#).

He knew from the television that COVID-19 could be bad for old people like his parents, so he stayed alone for two weeks after his diagnosis. Josh wasn't used to being alone when he felt sick because his mum and dad usually were very attentive. Bob left food, drink and medicine outside his bedroom door and would shout out to tell him when it was safe to come out. However, he needed to leave the bedroom to use the toilet and bathroom, as there is only one of these rooms in the house. The bathroom is

very cluttered, and Josh doesn't know how to clean it. He washed his hands with water but couldn't find any soap. This upset him, as he likes to be clean and worried about leaving the virus in the room. When Jane also tested positive for COVID-19 two days later, Josh blamed himself. Thankfully, her infection was mild and was managed successfully at home.

Joshua largely stayed in bed the first week because he felt so sick, but he felt better in the second week and was ready to become more active. Josh loves to watch television, but there is no television in his room. This meant he could also not access his gaming console, which is also a favourite activity. Josh quickly became bored and began to experience more negative thoughts, frustration and low mood. Dr O'Reilly maintained phone contact with the family throughout Josh and Jane's COVID-19 infection and arranged a follow-up appointment for them as soon as they left quarantine. Both were assessed to

have recovered and were back to their usual levels of function. All three members of the family had received both doses of the Pfizer vaccine along with a follow-up booster prior to their infection.

## Developing Long COVID

Josh returned to work as soon as he completed his quarantine and had seen Dr O'Reilly. Most of his workmates had returned after seven days of isolation (as per the government guidelines), and they were very glad to be 'back to normal' and to have him back on site. Josh was happy too but felt exhausted after his first day back at work and had a terrible headache. He took a sick day the following day, and Bob arranged a telehealth appointment with Dr O'Reilly. He advised Josh he might need to take more time off work before returning to rest, as it sounded like he wasn't 'fully over it'. Dr O'Reilly signed him off for a week, which Josh spent mostly at home watching television and gaming. He tried to attend work again the following week but again developed a headache and even worse fatigue. Josh also experienced muscle pain and stiffness, making him uncomfortable and less willing to move around the office for tasks. He didn't want to stay home anymore but felt his boss was getting upset with him for making mistakes or getting mixed up. Josh saw Dr O'Reilly again, who suggested he may need a longer recovery time due to his pre-existing medical conditions. Bob spoke to the employer and arranged for Josh to drop down to three days a week and work shorter hours (only in the morning) until he felt able to resume full-time duties. His boss was understanding as he said his own wife was really struggling with fatigue, and he wanted to do everything possible to keep Josh on board. However, Josh felt really bad about 'letting him down' and became teary and despondent at home.





**Leo had heard about Long COVID from his workmates.** Photo by [Juan Pablo Serrano Arenas](#) by [Pexels](#).

Joshua and his family hadn't really heard of Long COVID until his brother Leo mentioned it on the phone in a conversation with Bob and Jane. He said he had heard some people take longer to get better after COVID-19 so they might feel sick for a long time. Josh asked Dr O'Reilly about his next appointment,

who said he wasn't sure why some people took a long time to get over COVID-19. He had heard about it from some of his other patients. Still, he said it's not unusual for people to be tired for a long time after viruses. He reminded Josh his genetic condition might make him more susceptible to a long recovery. When Josh asked how long he would be sick, Dr O'Reilly said he didn't know, and there was no medicine he could give him to make him feel better. Josh was confused because Dr O'Reilly always knew how to make him feel better, and he worried that he would lose his job if he weren't working full-time like before. While Bob, Jane and his boss tried to reassure him it would be all right in time, he didn't really believe them.

***"I have to get better. They'll think I'm useless. They won't want me anymore."***

## Current Situation

Josh continues to feel constantly fatigued, has daily headaches most days, and his muscle pain and stiffness are now constant. He has put on seven kilograms since being diagnosed with COVID-19, and everything in life seems difficult. Given his slow recovery from the first one, Josh continues to seek Dr O'Reilly regularly, who has told them he really needs to avoid getting any further COVID-19 infections. So, he wears a mask

everywhere he goes, washes his hands multiple times a day and avoids going out in the community unless it's absolutely necessary. Any trips outside of his house are brief anyway due to his fatigue and usually result in him returning to bed upon his return. His work hours have now been reduced to two hours on two days of the week as this appears to be all he can currently manage. His work colleagues were very understanding but unsure what to say or how to help. So they avoid talking to him about it altogether. However, his boss remains supportive, which is important as Josh's wage helps his parent to cover the family's bills.

Bob and Jane are very worried about Josh's health and well-being as they believe he is sleeping too much and has become depressed again. While they have a lot of empathy for their son, they are also increasingly irritated at him for not helping around the house or doing anything other than working and sleeping. As Jane says, *"Sometimes its hard to know if its the COVID or if he's just being a bit lazy and blames it on that."*

However, Bob thinks *"he's putting all his efforts and energy into keeping his job, which is really important to him ... and us."* Josh wishes he never got COVID-19, and he often wonders what he did 'wrong' in getting it. He knows he was lucky not to have to go to the hospital, but he feels like Dr O'Reilly can't help him, so this could be his life from now on.

## *Life Roles*

Long COVID has had a negative impact on most of Josh's life roles. He wants to be a full-time worker again and values being a friend and community member. Josh feels particularly guilty about not being a good dog owner, as he knows Chumpy depends on him.

***"He's so sad when he doesn't walk ... and that's my fault"***

Role	Before COVID-19	Currently
Worker	Josh worked as an office assistant in a local business full time.	Continues to work in this position, but reduced hours (two hours per day on two days of the week)
Home Maintainer	Josh helped his parents with domestic activities such as housework, laundry and gardening. He could not complete most tasks independently but would work alongside Bob or Jane under their direction.	Not providing any assistance with domestic tasks.
Friend	Josh kept in touch with some friends from his time at Creative Links and occasionally met them in town after work. He also goes to football with a family friend (Jim) who also supports the local team.	He no longer sees any of his friends and cannot tolerate attending a full Australian Rules Football game (approximately three hours). Josh also worries about being exposed to COVID-19 in a crowd.
Family Member	Josh saw his brothers monthly at family gatherings and occasionally at their parent's home. He would also see extended family members on a less regular basis.	His brothers no longer visit his house, as they are concerned about the risk to their own children from the clutter and dilapidation of the property. He speaks with them by phone occasionally but misses seeing them. He has not had contact with his extended family since before the pandemic.
Community Member	Josh regularly visited the nearby supermarket for his parents, where the staff all knew him and would always have time to chat with him. He was also friendly with the bus driver, who regularly took him to work and back.	Josh doesn't see any of these community friends, as he no longer visits the supermarket or takes the same bus he used when working full time.

Pet Owner

Josh walked Chumpy twice daily and cleaned up after him in the backyard. He also attended all veterinary visits with his parents.

He no longer walks Chumpy because of his fatigue. Bob walks Chumpy when he can but can't always do this due to other commitments. Bob also finds it hard to walk him sometimes, as Chumpy is excitable and pulls on the lead (which Josh is strong enough to manage).

## Activities of Daily Living

In addition to changes in his life roles, Long COVID has negatively impacted many of Josh's activities of daily living.



*An interactive H5P element has been excluded from this version of the text. You can view it online*

*here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=121#h5p-4>

**Brushing Teeth.** Photo by [MART Productions](#) from [Pexels](#) /

**Morning Coffee.** Photo by [MART Productions](#) from [Pexels](#) /

**Gaming.** Photo by [MART Productions](#) from [Pexels](#)

Activity	Before COVID-19	Currently
Showering / Bathing	Independent for showering, but no one uses the bathtub due to difficulties with transfers. The bathroom has a separate shower cubicle and bathtub.	Independent, but requires a rest of 10 minutes afterwards to reduce breathlessness and 'recharge.'
Eating	Independent for feeding and drinking activities. No swallowing issues. He ate the same diet as his parents, which included mostly non-processed foods.	He is Independent but has increased his intake of sugary and processed food (including high caffeine/energy drinks). He believes this helps with his fatigue but acknowledges he has put on weight recently.
Walking / Moving Around	Independent. Able to walk around two kilometres at a slow but steady pace, but rapidly tires after this distance due to hypotonia.	Independent, but significantly reduced endurance. Josh becomes breathless after walking to the bus stop, which is 100 metres away from his home.

Communication	<p>Independent for everyday conversation. Good receptive language, particularly when plain language is used, and non-abstract concepts are being discussed. Able to express himself fluently with minimal impact on understandability for others. Josh has difficulties with auditory short-term memory and auditory processing but has developed compensatory strategies (such as writing instructions down and trying to find quiet areas for conversation). These strategies have been supported by his parents, teachers and employers for many years.</p>	<p>Fatigue has a significant impact on Josh's ability to communicate, both mentally and physically. He reports finding it hard to concentrate on what other people are saying to him, and his boss reports he gets overwhelmed with instructions more readily now. His family also report that his speech is less intelligible at times, but he tends to withdraw from the conversation if asked to pronounce himself more clearly. Josh is reluctant to ask people to repeat themselves at work if they think he is stupid and can't cope with this job.</p>
Driving / Public Transport	<p>Independent on familiar routes. Josh could catch the bus in all weather on specific routes after practising a couple of times with Bob or Jane. He needed someone to accompany him on unfamiliar routes or when catching the train to other locations for family gatherings or football matches.</p>	<p>Catches bus to and from work, located 20 metres from the bus stop. However, he needs to sit and rest at work / at home for 20 minutes after these journeys due to fatigue and breathlessness. He asks his parents to phone in sick to work on days of inclement weather or if he cannot find a mask. Josh waits for the next bus if he cannot get a seat or it is too crowded but feels increasingly anxious and frustrated if he misses more than one service.</p>

Money Management	<p>Independent for simple purchases with cash or 'tap and go'. Bob manages Josh's money and provides him with funds at request. Josh has a history of overspending, so Bob places any money not immediately needed into a separate saving account for him. Josh also contributes a third of his wages and benefits to the household bills and rent by mutual agreement with his parents.</p>	<p>Money management arrangements remain unchanged. Household bills and rent have increased sharply recently, and Josh's wages are decreased due to his reduced work hours. This has resulted in there being very little discretionary income for Josh, and the family are struggling with considerable financial pressure.</p>
Meal Preparation	<p>Supportive participation with Bob or Jane. Josh assisted with cooking meals and cleaning up most days, with prompting and support from his parents.</p>	<p>Josh is no longer assisting with meal preparation. His parents have tried to scale back the tasks they ask him to complete and believe his lack of participation is related more to motivation than physical ability.</p>
Shopping	<p>Independent with a brief shopping list. Josh visited the nearby supermarket three times a week and collect a small list of daily needs (such as milk, bread, and eggs). He was able to transport up to two bags of shopping back home (approximately a one-kilometre walk) and assisted in putting them away in the cupboards and refrigerator.</p>	<p>Josh only leaves the house for work or GP appointments and no longer participates in this task. Bob now completes this activity but finds it increasingly difficult due to his age and other commitments. As a result, the family does not always have access to fresh food.</p>

Healthcare	Supported participation with Bob or Jane. Josh's parents accompany him to all healthcare appointments and advocate for him when required.	Healthcare arrangements have not changed; however, neither Josh nor his parents feel comfortable with telehealth appointments. They often have to wait more than a week for a face-to-face appointment with Dr O'Reilly.
Rest / Sleep	Independent. Josh maintained good sleep hygiene and regularly attained 9-10 hours of restful sleep per night.	Josh is still in bed 9-10 hours per night, but his sleep is often broken, and he now wakes up earlier. Josh also requires additional sleep during the day. These naps last two or four hours, depending on his activity level, and there may be more than one during the day. He also now takes multiple rests sitting down following bursts of activity, which last 10-20 minutes at a time. Josh often says he doesn't understand why he is still so tired when sleeping so much.

## *Josh's Goals*

Josh is usually an optimistic person, and he still hopes that he will feel better one day. However, he doesn't believe anyone can do anything to make that happen at the moment. He would like help with the following goals:

1. Return to full-time hours at work
2. Not to feel so tired all the time
3. Go back to the footy with Jim



#### 4. Walk Chumpy every day

Bob and Jane would also like Josh to get more help with his symptoms of depression, but he does not want to work on this at the moment.

*“I just want my old life back.”*

## What does the evidence say?

### The current body of evidence.

- Rawlings and Beail<sup>1</sup> note there has been very little empirical research on Long COVID in this population to date, meaning evidence-based practice can only be based on assumptions that may or may not be valid.
- There have been no studies to date on the prevalence rate of Long COVID in people with intellectual disabilities<sup>2</sup>.

1. Rawlings, G.H., & Beail, N. (2022). Long-COVID in people with intellectual disabilities: A call for research of a neglected area. *British Journal of Learning Disabilities*, early view.
2. Shankar, R., Perera, B., Roy, A., Courtenay, K., Laugharne, R., & Sivan, M. (2023). Post-COVID syndrome and adults with intellectual disability: Another vulnerable population forgotten? *The British Journal of Psychiatry*, 222(1), 1-3. doi:10.1192/bjp.2022.89.

### **General impact of the COVID-19 pandemic.**

- Clinicians working with people with intellectual disabilities during the pandemic have observed greater distress and isolation for their patients, who are already at risk of disadvantage and poor health outcomes<sup>3</sup>). Families often took on greater responsibility for support during lockdowns or times of restriction<sup>4</sup>, while accessing information in plain language about public health orders and other mitigation measures was not always available<sup>5</sup>.

### **Risk factors.**

- Most available studies have identified a

3. Howkins, J., Hassiotis, A., Bradley, E., Levitas, A., Sappok, T., Sinai, A., . . . Shankar, R. (2022). International clinician perspectives on pandemic-associated stress in supporting people with intellectual and developmental disabilities. *British Journal of Psychiatry Open*, 8(3), E84. doi:10.1192/bjo.2022.49.
4. Navas, P., Verdugo, M.A., Martinez, S., Amor, A.M., Crespo, M., & Deliu, M.M. (2022). Impact of COVID-19 on the burden of care of families of people with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 35( 2), 577– 586. <https://doi.org/10.1111/jar.12969>
5. Embregts, P.J.C.M., Tournier, T., & Frielink, N. (2022). The experiences of psychologists working with people with intellectual disabilities during the COVID-19 crisis. *Journal of Applied Research in Intellectual Disabilities*, 35( 1), 295– 298. <https://doi.org/10.1111/jar.12916>

significantly increased risk of death from COVID-19 for people with intellectual disabilities in comparison to the general population<sup>6 7 8 9</sup>. However, Turk et al.<sup>10</sup> reported similar mortality rates from COVID-19 between these groups.

- Several studies indicate people with intellectual

6. Shankar, R., Perera, B., Roy, A., Courtenay, K., Laugharne, R., & Sivan, M. (2023). Post-COVID syndrome and adults with intellectual disability: Another vulnerable population forgotten? *The British Journal of Psychiatry*, 222(1), 1-3. doi:10.1192/bjp.2022.89.
7. Public Health England. COVID-19 Deaths of People Identified as Having Learning Disabilities – Summary. Public Health England, 2020 (<https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary>).
8. Majithia, M., & Ribeiro, S.P. (2022). COVID-19 and Down syndrome: the spark in the fuel. *Nature Review Immunology*, 22, 404–405. <https://doi.org/10.1038/s41577-022-00745-w>
9. Williamson, E.J., McDonald, H.I., Bhaskaran, K., Walker, A.J., Bacon, S., Davy, S. ... & Kuper, H. (2021). Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. *British Medical Journal*, 374, n1592. doi:10.1136/bmj.n1592.
10. Turk, M.A., Landes, S.D., Formica, M.K & Goss, K.D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, 13(3), 100942. doi:10.1016/j.dhjo.2020.100942.

disabilities (including Down Syndrome) are also at increased risk of contracting COVID-19, COVID-19-related complications (including acute respiratory distress syndrome or ARDS), a longer length of stay, hospitalisation and intensive care admission than the general population<sup>11 12 13</sup>. These increased risks have been attributed to the combined impact of immunological dysfunction, systemic inflammation, early aging and a higher incidence of respiratory infections in people with intellectual disabilities<sup>14 15 16</sup>.

11. Majithia, M., & Ribeiro, S.P. (2022). COVID-19 and Down syndrome: the spark in the fuel. *Nature Review Immunology*, 22, 404–405. <https://doi.org/10.1038/s41577-022-00745-w>
12. Baksh, R.A., Strydom, A., Pape, S.E., Chan, L.F., & Gulliford, M.C. (2022). Susceptibility to COVID-19 Diagnosis in People with Down Syndrome Compared to the General Population: Matched-Cohort Study Using Primary Care Electronic Records in the UK. *Journal of General Internal Medicine*, 37, 2009–2015. <https://doi.org/10.1007/s11606-022-07420-9>.
13. Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of COVID-19 on individuals with intellectual disability in the United States. *New England Journal of Medicine*, March 5, doi: 10.1056/CAT.21.0051
14. Majithia, M., & Ribeiro, S.P. (2022). COVID-19 and Down syndrome: the spark in the fuel. *Nature Review Immunology*, 22, 404–405. <https://doi.org/10.1038/s41577-022-00745-w>
15. Amin, M.A., Khan, I.I., Nahin, S., Bonna, A.S. Afrin, S., & Hawlader, M.D.H. (2022). COVID-19 hospitalisation with later long COVID in a person with Down Syndrome. *Clinical Case Reports*, 10,

### **Working with people with intellectual disabilities experiencing Long COVID.**

- Shankar et al.<sup>17</sup> provide an overview of the unique challenges associated with Long COVID for people with intellectual disabilities. These patients can find it hard to identify and discuss their symptoms due to cognitive and communication difficulties. Neuropsychiatric issues such as depression, anxiety, delirium and psychosis are more common in people with intellectual disabilities and may be pre-existing conditions for those contracting COVID-19. Therefore, identifying the impact of Long COVID on people with intellectual disabilities may require increased vigilance about subtle changes in behaviour, function, prescribing or support needs. Observations about these changes may be made by clinicians, carers or family members. For an overview of research priorities in this area,

e06425. doi:10.1002/ccr3.6425.

16. Atkinson, T.P. (2022). Defective Immune Response to SARS-CoV-2 Immunization in Down Syndrome Correlates With Increased Susceptibility to Severe Illness With Infection. *The Journal of Infectious Diseases*, 226 (5), 755-756. <https://doi.org/10.1093/infdis/jiac237>
17. Shankar, R., Perera, B., Roy, A., Courtenay, K., Laugharne, R., & Sivan, M. (2023). Post-COVID syndrome and adults with intellectual disability: Another vulnerable population forgotten? *The British Journal of Psychiatry*, 222(1), 1-3. doi:10.1192/bjp.2022.89.

please see Appendix A of this article.

#### **Available case studies or series.**

- Amin et al.<sup>18</sup>: A 42 year old woman with Down Syndrome, hypothyroidism and diabetes was admitted to a hospital in Bangladesh (n=1). Admitted to the hospital on Day 11 following infection and experienced worsening respiratory symptoms, fever, myalgia and cough over time. She remained in the hospital for 16 days and required CPAP treatment. At a three-month follow-up appointment with her community doctor, she described continuous myalgia in all limbs and joint pain, particularly in her feet. The patient had no prior history of joint or muscle pain. Painkillers and non-steroidal anti-inflammatory drugs were prescribed to manage this problem, but no other treatment was described. Along with greater attention to early identification and treatment of COVID-19 infections in people with intellectual disabilities, the authors recommend an annual musculoskeletal examination for all people with Down Syndrome be offered as standard practice.
- Perera et al.<sup>19</sup>: Cases of COVID-19 mortality in

18. Amin, M.A., Khan, I.I., Nahin, S., Bonna, A.S. Afrin, S., & Hawlader, M.D.H. (2022). COVID-19 hospitalisation with later long COVID in a person with Down Syndrome. *Clinical Case Reports*, 10, e06425. doi:10.1002/ccr3.6425.

19. Perera, B., Laugharne, R., Henley, W., Zabel, A., Lamb, K., Branfo

British and Irish people with intellectual disabilities (n=66). This cohort was younger (mean age 64 Years) than the general population and experienced higher rates of moderate-to-profound intellectual disability, epilepsy, mental illness, dysphagia, Down syndrome and dementia. Some variability was identified between groups with different severity of intellectual disability (mild-moderate-severe). The authors comment on the urgent need for further research in this area, particularly around the compounding impact of comorbidities.

#### **Upcoming research.**

- A follow-up survey for the [Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing \(IDS-TILDA\)](#) is currently underway with specific questions regarding Long COVID in this population.

#### **Further information.**

- Eusebio, K. (April 24th, 2020). [Why COVID-19 confinement is hitting people with intellectual disabilities hard | World Economic Forum \(weforum.org\)](#)<sup>20</sup> World Economic Forum, Geneva.

rd, D. ... & Shankar, R. (2020). COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study. *British Journal of Psychiatry Open*, 6, e123.

20. McCarron, M., Allen, A., McCausland, D., Haigh, M., Luus, R., Bavussantakath, F.R. .... & McCallion, P. (2021) The impact of

- National Task Group on Intellectual Disabilities and Dementia Practices. (2022, October 5). Advisory on Long-COVID and Impact on Cognitive Function in Adults with Intellectual Disability. Available at [www.the-ntg.org](http://www.the-ntg.org).

## References

COVID-19 on people ageing with an intellectual disability in Ireland: Protocol for a follow-up survey. Health Research Board Open Research, 4, 95. doi: 10.12688/hrbopenres.13340.2. PMID: 34622141; PMCID: PMC8456373.



# 10. Sophia Sparks

*By Anonymous, Kelli Nicola-Richmond & Danielle Hitch*



*Sofia runs her own auditing business. Photo by [Jopwell](#) from [Pexels](#).*

Sophia is a 32 year old woman who lives in inner-city Sydney. She is the daughter of an Indian mother and an Australian father. Sophia runs her own auditing business, which she started 9 months ago. Before this, she was employed in the finance sector across several leadership positions. Sophia

enjoys reading and walking with her friends in the local area. She also enjoys connecting with her Indian heritage with her mother and daughter, and they often attend cultural events together.

## Home Life

Sophia lives with her partner (Neil, aged 38), daughter (Eliza, aged 6) and two Persian cats (Tia and Beau) in an inner suburb of Sydney. Sophia studied finance at Sydney University, which is where she met her husband Neil. They dated for four years and got married



*Neil and Sophia love their inner-city neighbourhood. Photo by [Bell Co](#) from [Pexels](#).*

when they were both 25 years old. Neil and Sophia own their home and have a healthy income that allows them to live a comfortable lifestyle. Neil and Sophia are very proud of their home and always ensure it is neat, tidy and well-maintained, inside and out. Sophia's parents are both retired professionals who live nearby in Newtown. They talk to and visit Sophia once or twice a week and are loving and supportive. Her parents are also actively involved in caring for their granddaughter Eliza and support Sophie with childcare if her usual after-school arrangements are unavailable or she is working long hours. Sophia's sister (Alice, aged 28) lives in Melbourne with her husband and two young children.

***“With both of us trying to work full time, life is hectic. We are lucky to have Mum and Dad nearby to help.”***

## Community



*Eliza goes to after-school care five days a week. Photo by [Wilmer22](#), CC BY-SA 4.0 via Wikimedia Commons*

Sophia lives in the suburb of Balmain, near Sydney Harbour. Balmain is a quiet, leafy suburb with nice parks and harbour-side walks. It is a quick commute into the Central Business District, where both Sophia and Neil work. They use public transport via the harbour ferries or buses to commute to work and their own cars for

all other transport, although traffic in the area can make travel times longer than they would like. Sophia and her family love living in Balmain and the easy access to the water, where they have a small sailing boat that they use on the weekends. Eliza attended kindergarten in the local area and is now at the local Catholic primary school. Sophia has a wide social group based on the parents she knows from school and also contacts from her workplace.

***“We love the water and spend time on the harbour whenever we can.”***

## Health

Before the COVID-19 pandemic, Sophia had always been fit and healthy. She attended the gym three mornings a week before work, walked on the weekends with friends and regularly went sailing and swimming. She had no pre-existing illnesses or disabilities. She and Neil would like to have another baby but have not been able to get pregnant. Recently they have been

talking about trying IVF, although they have put this on hold since she developed Long COVID.

## COVID-19

### *Acute Infection*

Sophia contracted COVID-19 in early December 2021 at a workplace Christmas party. The first few days felt very similar to a seasonal cold, as she experienced a runny nose, cough, sore muscles, headache and exhaustion. She also experienced some loss of taste and smell, which she found disconcerting. While her sense of taste and smell returned in the third week, she noticed some foods '*didn't taste quite right*'. In the second week, the infection began to affect her lungs more severely, and breathing became more difficult. Sophia had never experienced breathlessness before, and being unable to get 'enough air' made her feel very anxious. She also noticed she was becoming more stressed generally about her symptoms and was beginning to wonder if she would ever get better.

Despite feeling very poorly, Sophia went ahead with all the events and activities of Christmas week as usual because she didn't want to let Eliza down. While no longer infectious, she also found it difficult to deal with the questions and suspicions of others about her symptoms. On several occasions, she was berated by others who refused to believe she had clearance to leave quarantine and told her she was putting everyone around her at risk. Her breathlessness improved slightly in the fourth week but returned whenever she undertook more than very gentle exercise. Sophie continued to experience a runny nose and exhaustion, but her cough and muscular soreness had resolved by the end of December.

## *Developing Long COVID*

After the rush and bustle of Christmas, Sophia became more despondent about her ongoing symptoms. Her exhaustion, breathing difficulties and congestion were constant, and she was finding it harder and harder to concentrate. Even sitting in front of the television at night was too demanding, as she could now not follow the storylines of her favourite programs. Reading was virtually impossible, and she simply didn't have the energy to go to the park or down to the harbour with Eliza. Neil began taking on these tasks for her so her daughter could still enjoy her summer holidays, but Sophia felt increasingly upset about being '*left behind*' in the house while they went out and had fun together.

Sophia had returned to work around a month after becoming infected, having used a combination of sick and holiday leave over the festive period. She hoped that returning to a routine would help her '*snap out of it*', and she was impatient to return to her normal life. Her



*Sophia with her colleagues at work. Sofia runs her own auditing business. Photo by [Jopwell](#) from [Pexels](#).*

GP had advised her to return to work gradually and slowly increase the amount of activity she completed each day. However, Sophia was concerned that her business would suffer without her playing a more active role and attempted to return full-time immediately. It soon became apparent that she was making many mistakes at work, and she felt mortified that they were being noticed and commented upon by her colleagues. Their criticism felt like discrimination and bullying, and it was left up to Sophia to try to explain Long COVID and how it was impacting her capacity to her colleagues. While she could take time away from work, she did not feel able to

delegate her responsibilities to others, which left significant gaps in the workflow that led to conflict with other staff. Sophia's two best employees decided to leave the business due to these issues, meaning she needed to quickly go through the recruitment process to fill their roles. While her colleagues were generally very supportive of her, Sophia felt immense pressure to work harder and speed up her recovery. She has begun to wonder about selling the business but does not want to lose all the hard work she put into its founding and development.

***“It was just like I'd be walking around and I'd go to do something and then I'd be like, hey, wait, what am I doing? I'd be trying to remember processes within the computer system, which I've used for years and years.”***

Sophia just couldn't understand why she was still so unwell when everyone else she knew had made a quick and full recovery from COVID-19. Initially, she had held out hope these symptoms were just a hangover like sometimes happens after a 'bad cold', but this was rapidly ebbing away.

***“What was wrong with me? I don't usually just drop my bundle when things get tough.”***

Three weeks after returning to work, Sophia experienced a significant relapse in breathlessness and exhaustion. Aside from attending work, she spent most of her time asleep in bed or on the couch. Now she found she was beginning to have micro naps in the office and (even more concerningly) when driving her car. Sophia began to experience panic attacks while breathless and during meetings. While she had a history of these attacks previously in life, she found she could no longer use the management strategies that had previously served her so well. Although she could physically breathe, she didn't feel as if the oxygen was going where it needed to go. Lifting and bending became extremely challenging and walking to the corner shop and back resulted in her immediately needing to sleep. Every moment of the day was clouded with brain fog,

which she described as feeling similar to jet lag after a 24-hour flight. Any stress or fatigue trigger seemed to bring on more severe congestion, leading to her needing to have extra rest for another three or four days.



Sophia misses her old social group.  
Photo by [Aline Viana Prado](#) from [Pexels](#).

Socialising was also extremely tiring, as she no longer wanted to travel to see anyone and couldn't keep track of face-to-face or telephone conversations. As a result, she feels that her friends are drifting away as they don't know how to help her. One of her friends also told her that she should "check her priviledge" because she is far better off than most people and should focus her attention on helping people who are

"really doing it tough" instead of feeling sorry for herself. While their tough love approach was intended to be helpful, it only made Sophia feel more anxious, despondent and ashamed. Only two people in her personal life seemed to really understand her condition and accommodated her needs – her mother and a long-time friend (Rosie). Sophia lost her patience with people who tried to offer amateur medical advice, recommended diet changes or supplements or seemed to need constant reminding that she had Long COVID as they forgot about her invisible disability.

***"When you have Long COVID, just catching up with one friend for a coffee can be an overwhelming experience that you have to save up energy for. When you add driving onto a simple catch-up, it gets even more draining, and may even require you to budget an entire day off to recover."***

She also felt a growing reluctance to socialise outside of her family because Sophia was terrified of catching COVID-19 again. When she did catch up with friends, she insisted on outdoor venues and prior rapid antigen testing (RAT). Still, as Australia began to relax community restrictions, she found people were less willing to accommodate her needs. Sophia also attempted to maintain mask-wearing and other restrictions in her workplace but grew tired of fighting resistance from her staff and relented. Her inability to enforce these precautions means she sometimes feels unsafe in the workplace.

***“Everyone else has just moved on. COVID is over, isn't it? Not for me, but what right do I have to complain – I'm so much better off than most people”.***

It became obvious to Sophia after three months that her symptoms, such as fatigue, congestion, breathlessness and poor exercise tolerance, were not going away any time soon. The GP that had been issuing doctors certificates for work confirmed that Sophia now had what was considered ‘Long COVID’ but told her there were few guidelines and no medications available to treat it. After four months, her GP decided to do follow-up tests to exclude any other explanations for her symptoms. These included



*The majority of Sophia's test results were normal. Photo by [Pavel Danilyuk](#) from [Pexels](#).*

blood tests, a lung scan, and an electrocardiogram (ECG). Her B12 levels were found to be low, but this issue was resolved after Sophia received B12 injections. Both her lung scan and ECG



were reported as normal. Sophia also began to notice new symptoms emerging. She was now very sensitive to light and sound and often experienced pins and needles in her hands and feet. While she knows some of these sensations may be due to stress and anxiety, Sophia wonders if her sensory sensitivity is related to her COVID-19 infection. She mentioned this problem to her GP, who said he believes she is focusing too intently on her symptoms, and this is causing her to be hypervigilant about normal bodily functions. While Sophia acknowledges this could be the case, she still feels that something has fundamentally changed with her health and well-being.

***“I’m not the same person since COVID-19... my body is different... and I know my body better than anyone else”.***

However, Sophia did accept the offer of a mental health care plan from her GP and went to see a psychologist. While the psychologist was very supportive, she found talking about her Long COVID made her feel worse, so she stopped going after three sessions. The GP also referred her to two different Long COVID clinics and one fatigue clinic, saying he was hopeful at least one of them would be available to provide her with specialist advice. When Sophia followed up with each of them, all of their waiting lists were at least 8-12 months, and there was no guarantee the Long COVID clinics would continue to receive funding. She independently went to see a physiotherapist for hand pain, which developed due to her new habit of working on her laptop while resting in bed as a strategy for preserving her energy. The hand pain was so severe it impacted her ability to do her job. The physiotherapist told her there was nothing wrong with her hand muscles and recommended movement and exercise to improve blood flow into the limbs. When Sophia asked how to manage this in light of her fatigue, he said that wasn't his area of expertise and suggested she go elsewhere for more specialist advice. While she could understand some level of ignorance from the general public,

Sophia felt the lack of education about Long COVID she encountered from some health professionals was inexcusable given the rapidly increasing number of patients they must have seen with this condition.

***"I don't expect them to know everything, but by now they should no something!"***



*Sophia's respiratory specialist gave her advice on increasing her activity safely. Photo by [Anna Shvets](#) from [Pexels](#).*

Sophia's GP diagnosed her congestion as asthma and prescribed Symbicort and Nasonex. After months of experiencing severe congestion, she asked to be referred to a respiratory physician and was lucky enough to get an appointment within 8 weeks. The respiratory physician ordered a spirometry test and told Sophia to stop taking the asthma medication for now and return in a few months for a review of her asthma diagnosis. She believed the congestion was caused by bronchitis, and she

prescribed Sophia a low-dose antibiotic three times a week to stop the overproduction of mucus. The antibiotics were very effective, and for the first time in her recovery, Sophia felt hopeful and reassured. With the congestion gone, she felt more confident about increasing her exercise. The respiratory physician told her that increased physical activity (particularly walking up hills) was recommended to improve her lung function. She gave her a clear action plan as to how to increase her exercise without overdoing it. No doctor up to this point

had offered any guidance around exercise, and while still very compromised, Sophia has managed to slowly increase physical activity in recent weeks.

## Current Situation

Sophia now has a regular exercise routine – a 30-minute walk and stretch every morning – which helps with the hand pain and congestion, as well as general health. Some days she can't manage it, but other days she does 45 minutes or an hour of walking, so it balances out. She has realised that health professionals are limited in what they can offer, so she is taking advice on pacing her activities from a new friend with Long COVID (Lela) who has been receiving care from a Long COVID clinic. While it's not ideal for getting second-hand information, she feels it is the closest thing to medical advice she can access right now. Sophia tries not to think about her Long COVID too much, instead focusing on what she can control, such as seeing friends more often and achieving her work and exercise goals.

***"I'm learning to break up normal activities into sections and introduce breathing time where there normally isn't any".***

Sophia is looking for a GP that can help offer holistic health advice that supports her in making right decisions for her health and well-being instead of a more traditional biomedical approach. She would particularly like some advice on participating in work more sustainably and whether to make an insurance claim through her superannuation for lost income. Sophia would also like to see a doctor that is up to date with all the Long COVID literature so that the burden doesn't fall onto her – she no longer wants to have to educate the people she seeks care from. She wants someone who is willing to listen to all the evidence and experiences she has had

during this pandemic and offer advice tailored to her individual situation.

***“Honestly, that’s not my job – I’ve got more than enough to do!”***

## **Life Roles**

Since developing Long COVID, Sophia has experienced changes in many of her life roles.

<i>Role</i>	<i>Before COVID-19</i>	<i>Currently</i>
<i>Worker</i>	Sophia was a full-time business owner and principal auditor – an extremely demanding, emotionally taxing role.	She now works part-time (approximately 20 hours per week), and the business is taking in less work to accommodate her cognitive and rest needs.
<i>Home Maintainer</i>	Sophia previously shared household tasks with Neil. Sophia did most of the cooking and washing during the working week.	Neil now undertakes the bulk of the housework and home maintenance. Sophia still tries to prepare the meals, given that she works fewer hours.
<i>Friend</i>	Sophia had a group of close girlfriends that she often saw for group walks. She and Neil also socialised most weekends with people from the sailing club. Sophia also had two work colleagues she usually had lunch with and occasionally saw outside of work.	Sophia has lost contact with many of her previous friends and work contacts. However, she has become close with Lela, who also has Long COVID and supports her. She has also stayed in close, supportive contact with a friend that she has known since school (Rosie), and they have recently resumed walking together (albeit short distances).
<i>Family Member</i>	Sophia would often drop by her parents' place socially, and she and Neil also hosted them for dinner every Thursday. Her parents also assisted her with incidental child care. Every six months or so, Sophia would travel to Melbourne for work and would extend her stay by a few days to catch up with her sister (Alice)	Sophia continues to see her parents frequently, who have been very supportive (particularly her mother). However, Thursday dinners have not resumed, and she feels as though they and her husband have become her carers to some degree. Her sister calls to check on her twice per week, but Sophia has not seen Alice since contracting COVID-19.

<p><i>Community Member</i></p>	<p>Sophia was a member of the Sailing Club executive committee and frequently volunteered at events held at Eliza's school.</p>	<p>Sophia has not resumed these community activities since contracting COVID-19. She hopes to return to sailing soon but feels that she will need to limit her community involvement for some time. She has, however, managed to participate in some brief online events recently.</p>
<p><i>Caregiver</i></p>	<p>Sophia previously took Eliza to most of her extracurricular activities and would often help her prepare for school. Neil has always liked to get Eliza into bed at night and read to her.</p>	<p>Neil now helps more with the day-to-day parenting and running around for Eliza. Neil has reduced the previously long hours he spent at work so that he can be home more to help, but he would also like to return to his original working hours.</p>



*An interactive H5P element has been excluded from this version of the text. You can view it online here:*

<https://oercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=297#h5p-7>

Craftwork. Photo by [Anna Shvets](#) from Pexels / Driving. Photo by [Daniel Andraski](#) from Pexels / Shopping Delivery. Photo by [RODNAE Productions](#) from [Pexels](#).

## Activities of Daily Living

Along with these changes in her life roles, Long COVID has negatively impacted many of Sophia's activities of daily living.

<i>Activity</i>	<i>Before COVID-19</i>	<i>Currently</i>
<i>Showering/ Bathing</i>	<i>Independent and typically takes a shower.</i>	In the early stages of Long COVID, Sophia stopped showering every day because it was too exhausting and didn't feel necessary. Her partner complained, so she tried to direct her energy and time towards showering. While she can complete the task now, it still takes her longer and leaves her feeling more drained.
<i>Eating</i>	Sophia and Neil would typically prepare most meals at home during the week and go out for breakfast and dinner at least once on the weekend. Sophia was committed to the family eating very healthy food.	Sophia eats much more take-away food now, particularly for tea, when she has spent all her energy on the day.
<i>Walking/Moving around</i>	Sophia was very active, walking 5 km at least three times per week and attending the gym for 45 minutes twice weekly. She also sailed on the weekends.	She has spent the last three months building up her walking capacity to 30 minutes a day, but there are still 2-3 days per week she cannot manage that distance.
<i>Personal Hygiene/ grooming</i>	Sophia prided herself on being well groomed, attending the hairdresser consistently every four weeks for a trim and colour.	Sophia no longer visits the hairdresser for fear of catching COVID-19 again and due to the extra effort required to get there. She can maintain an acceptable level of hygiene and grooming but feels 'scruffier' than she did previously.

<i>Sexual activity/ intimate relationships</i>	Sophie and Neil had a strong relationship with regular opportunities for sexual activity and intimacy.	Sophia's fatigue has greatly reduced her ability to participate in sexual activity. Her brain fog also impacted the energy she has available for emotional conversations and intimacy. Both she and Neil feel this has negatively impacted their relationship.
<i>Driving/public transport</i>	Sophia previously caught the ferry or bus to work in the city and drove at all other times. She did not experience any significant challenges with community mobility.	Driving requires a high concentration level, and doing this activity for more than 20 minutes at a time completely drains Sophia. She often feels unsafe driving due to fatigue and has transitioned to working from home some days as a management strategy. Sophia also avoids public transport due to the perceived heightened risk of contracting COVID-19 again.
<i>Money management</i>	As a dual-income family, Sophia and Neil had a high income that allowed them to spend fairly freely. They would typically take an overseas trip once a year to see friends and show Eliza the world.	Sophia's income has halved due to the impact of both the pandemic and her Long COVID on her business. Neil's income remains healthy, but they now have to watch their spending more closely than they used to and cannot afford some activities they used to enjoy.
<i>Shopping</i>	Sophia enjoyed going to the supermarket, typically early on a Sunday morning, so that she could be planned and ready for the meals for the week.	Sophia orders groceries online, and they get delivered to her doorstep. However, even logging on to make the order sometimes can feel overwhelming, and she finds it hard to plan what she might need for multiple days.



<i>Rest/sleep</i>	Sophia was active and energetic and would consciously limit her time in sedentary activities. She would retire to bed at about 11 pm, usually sleeping soundly until 6 am.	Sophia needs much more rest time and does not sleep soundly at night. While she still goes to bed around 11 pm, she is now lucky to get 4 hours of sleep per night. She gets up and watches Netflix when she can't sleep so she doesn't disturb Neil, and she feels like she is wasting her time on such meaningless activities.
<i>Caring for others</i>	Sophia was responsible for most of the caregiving during the week for Eliza when she was not in after-school care.	Neil now contributes the most to getting Eliza ready for school and running her to activities. He continues to take responsibility for her night-time routine, as this is the time of day when Sophia is most fatigued.
<i>Communicating with others</i>	Sophia was able to communicate with anyone independently and could modify her communication to suit the person she was speaking with.	Fatigue affects Sophia's ability to retain auditory and visual information. At the end of long meetings, Sophia often gets flustered and does not know how to wrap up. She is improving at recognising the warning signs when communication is not going well and knows to return to conversations when less fatigued.
<i>Leisure / Recreation</i>	All of Sophia's recreational tasks were active and physically demanding. They were all undertaken with family or friends.	While waiting for her health to improve sufficiently to return to her previous levels of exercise, Sophia began working on small art and craft projects.

However, Sophia does not perceive all of the changes in her life as negative. Long COVID has, in some ways, also provided her with new opportunities and the ability to re-evaluate her life.

**“Since getting Long COVID, my life has been emptied of a lot of the activities I enjoyed but also a lot of activities I didn’t enjoy but did because it was expected of me. In some ways, it’s a nice break from responsibilities. I try to focus on things I can do now that I would never have made time for before Long COVID, like seeing more of my family, watching sport, dabbling in some art and craft activities. My carbon footprint is a lot lower now, which helps with my environmental conscience. And it’s made me see which people in my life really care about me and which people were just exploiting my goodwill. I think it’s taught me a lot about what I value and what I am willing to spend energy on when I have so little of it”.**

## **Sophia’s Goals**

While Sophia feels that she is slowly improving, she still wants to work with health professionals who are knowledgeable about Long COVID on the following goals (in no particular order):

- Developing better strategies to deal with her brain fog and juggle multiple tasks more effectively
- Return to the gym, sailing and her pre-COVID level of fitness
- Engaging with wholistic health care that offers her multiple options for treatment and management
- Better balance of all the different demands on her energy and time
- Better mental health, and in particular, feeling less anxious and stressed

*"I just want people to know that Long COVID is incredibly complex. It affects every dimension of daily life and scars relationships in ways that I don't think most people will ever understand. We have to invent our own culture and ways of doing things to exist and feel safe in the world".*

## What does the evidence say?

### What is 'brain fog'?

- People with 'brain fog' experience forgetfulness, difficulty concentrating, dissociative phenomena, cognitive 'slowness', greater cognitive effort, communication difficulties, 'fuzziness', dizziness, myalgia, word-finding difficulties, pressure and cognitive fatigue [1,2]
- Brain fog is not unique to Long COVID – it is associated with various other conditions, including psychiatric, neurodevelopmental, autoimmune and functional disorders [1].

### Prevalence of brain fog

- A population-based study (n=2696) found a prevalence rate of 62.3% for brain fog in people with Long COVID [4]. Female sex, respiratory symptoms in the acute phase and intensive care

admissions were significantly associated with developing 'brain fog'.

### **Consumer experience of brain fog**

- A UK qualitative study of people with Long COVID (n=50) identified X themes: ambivalence about the appropriateness of the term 'brain fog'; rich descriptions of neurocognitive symptoms; fluctuations in symptoms over time; profound psychosocial impact on multiple areas of life; feelings of guilt, shame and stigma; self-management strategies; challenges navigating the healthcare system and the search for physical causes [3].
- A study of fifteen Americans with Long COVID highlighted that running a household, driving, employment, and multitasking were particularly difficult due to the synergistic nature of brain fog and overall fatigue [5]. Relationships were also significantly impacted, both within and externally to their family.

## **References**

1. McWhirter, L., Smyth, H., Hoeritzauer, I., Couturier, A., Stone, J., & Carson, A. (2022). [What is brain fog?](#) Journal of Neurology, Neurosurgery & Psychiatry, Online First: 06 December 2022. doi: 10.1136/jnnp-2022-329683
2. Jennings, G., Monaghan, A., Xue, F., Duggan, E., & Romero-Ortuno, R. (2022). [Comprehensive clinical characterisation](#)

- [of brain fog in adults reporting Long COVID symptoms](#). *Journal of Clinical Medicine*, 11(12), 3440.
3. Callan, C., Ladds, E., Husain, L., & Greenhalgh, T. (2022). [‘I can’t cope with multiple inputs’: a qualitative study of the lived experience of ‘brain fog’ after COVID-19](#). *BMJ Open*, 12, e056366. doi: 10.1136/bmjopen-2021-056366.
  4. Asadi-Pooya, A., Akbari, A., Emami, A., Lotfi, M., Rostamihosseinkhani, M., Nemat, H., Barzegar, Z., Kabiri, M., Zeraatpisheh, A., Farjoud-Kouhanjani, M., Jafari, A., Sasannia, S., Ashrafi, S., Nazeri, M., Nasiri, S., & Shahisavandi, M. (2022). [Long COVID syndrome-associated brain fog](#). *Journal of Medical Virology*, 94, 979-984. doi:10.1002/jmv.27404.
  5. Chasco, E.E., Dukes, K., Jones, D., Comellas, A.P., Hoffman, R.M., & Garg, A. (2022). [Brain Fog and Fatigue following COVID-19 Infection: An Exploratory Study of Patient Experiences of Long COVID](#). *International Journal of Environmental Research and Public Health*, 19(23),15499. doi:/10.3390/ijerph192315499

# 11. Jesse Haslop



***Jesse Haslop on his way to class.***

Photo by [Keira Burton](#) from [Pexels](#).

*By Emily Rawlings &  
Danielle Hitch*

Jesse (shortened from Essien) is a 26-year-old man who emigrated to Australia from Ghana with his family as an infant. His mother is Ghanaian and his father is South African. After

completing high school, he took a gap year to travel and spend time with his extended family in Ghana. Upon his return to Australia, he worked in the construction industry as a labourer for four years and then completed a Certificate IV in Engineering at TAFE. His success in that course led to him enrolling in a degree in Electrical Engineering, and he is now in his second year of study. He often attends live music concerts and is a dedicated and passionate fan of the Melbourne Victory soccer club.

***“I’ll never forget how hard I worked as a labourer ... those guys are heroes. Every day at uni is a reminder of how far I’ve come”.***

## Home Life

Jesse lives with two male flatmates in a large multi-storey apartment complex in the city. He is friends with one of his flatmates but the other flatmate is new and he doesn’t know him as well. Most of his current friends are from his university

course, but he also hangs out with people from his TAFE and labouring days. Jesse lost touch with many of his high school friends during his gap year but would like to catch up with them again sometime.

Jesse's mother and father still live in his childhood home in the outer Western Suburbs, and all his five siblings (three brothers and two sisters) are still living at home. He has a close relationship with his family, phoning them every day and visiting at least once a week. Jesse also has regular contact with extended family in Ghana online but has no other family members living in Australia. His mum has been in remission from breast cancer for the past year but experienced serious side effects from her chemotherapy which have not fully resolved.

Jesse does not have a partner currently, having recently broken up with his long-term girlfriend. He feels some pressure to get into a new relationship, partly due to pressure from his parents and partly because many of his friends are getting married. While he is active on dating apps, he finds speaking to potential partners stressful due to his shy and quiet personality.

***“My friends all say I should work on my ‘swagger’, but it’s not me ... and there don’t seem to be many quiet or shy girls online.”***

## Community



**Queen Victoria Market.** Photo by [Maxio](#) from [Pexels](#).

**Queen Victoria**  
**Market.** Photo by [Maxio](#)  
[Aeson](#) from [Pexels](#).

Jesse lives in Melbourne, which is a major Australia city with a population of 5 million people. The part of the city he lives in is home to many local and international students, and he loves the multicultural character of his local community. There are also many local shops, venues and facilities which cater specifically to students, which are very convenient for socialising after classes. Jesse has generally found the community a friendly place to which he feels a strong sense of belonging. However, he has experienced racist comments and verbal abuse from time to time on the street and in social venues.

***“I try not to take it on board – it’s their problem not mine – but it hurts. This is my city as much as theirs”.***

Jesse and his flatmates live near a public transport hub and the local market and he spends much of his free time out and about. He enjoys the outdoors and often sits in the city’s parks and gardens to study and relax. Jesse also has a student membership to the university gym and the local swimming baths, and where he exercises 2-3 times per week.

The main downside to living in this community is the cost of living, particularly as a full-time student. Jesse receives a government allowance and picks up casual hospitality work at the uni when he can. He is the first to admit that he struggles with budgeting, and often has to cut back on spending in the days leading up to his next payment. Jesse also worries about



his ability to continue paying rent in the apartment due to cost of living pressures.

***“Everything is just going up and up and up... there are days when I don’t eat just to make it through to the next pay day”.***

## Health

Jesse has generally experienced good health throughout his life. He had episodes of childhood illness (including chickenpox and hand-foot-mouth disease) but recovered quickly and without complication. Jesse played a lot of sports during his teenage years and recovered quickly from the minor musculoskeletal injuries he had from time to time. He had a bout of glandular fever aged 16 during an outbreak at his school. While the acute symptoms quickly subsided, he experienced significant fatigue for a further 6 months which led to the school allowing him accommodations for his end-of-year exams. However, all his symptoms had resolved by the beginning of the following year.

***“Apart from the glandular fever I just don’t get sick. And I’m not a sook that runs to the doctor for every little thing.”***

# COVID-19

## *Acute Infection*

Jesse managed to avoid COVID-19 for the first two years of the pandemic, which he attributes to the prolonged and strict lockdowns in Melbourne. He was very careful to comply with all public health orders at this time and finds it bewildering that his flatmates and some other



***Jesse complied with all public health orders during lockdowns.*** Photo by [Karique Rocha](#) from [Pexels](#).

friends did not take them more seriously. Jesse was often teased for continuing to wear a mask in public after they were no longer mandatory but felt compelled to protect other people in the community.

***“I get it ... you want to get back to normal life, but we have to protect people like my Mum.”***

However, Jesse contracted COVID-19 in March 2022 as part of the initial Omicron wave. He believes he caught it from his flatmate, and at that point, it was virtually unavoidable because “everyone had it”. Jesse’s symptoms were initially quite mild, with only three days of headache, aching, fatigue, and a runny nose. The only unusual symptom he experienced was an extensive torso rash, which also disappeared after three days. He did not attend the doctor or take any medications, as he felt able to manage his symptoms at home. Jesse was initially relieved to recover quickly as it was the beginning of the uni year and he did not want to get behind in his studies.

## ***Developing Long COVID***

However, as time wore on Jesse struggled to return to complete health. He was still feeling significant fatigue and spent much of his free time resting or sleeping in his bedroom. He also continued to have frequent, strong headaches along with dizziness which had never been a problem for him before. Despite his best efforts, Jesse was falling behind in his coursework, and experiencing difficulties with his concentration and memory. The trouble he was having with his studies was noticeable to his tutors, two of whom expressed concern to him about his performance.

***“They were trying to help, but it just put more pressure on me. And my Dad just thought I was being lazy”.***



***Studying got harder and harder.***

Photo by [Keira Burton](#) from [Pexels](#).

His flatmate suggested he go see a doctor, and Jesse made an appointment at the university clinic in July 2022. Upon examination, his blood pressure was 150/90 and his resting heart rate was 120 beats per minute. The doctor explained changes to blood pressure and heart rate were commonly found after COVID-19, but acknowledged it was a bit more unusual after four months. She ordered a range of blood tests and asked Jesse to come back in two weeks with some heart rate and blood pressure readings from his

smartphone. However, she said it was probably just done to

stress about upcoming examinations or 'white coat hypertension' because he so rarely went to the doctor. Given he was fit and young she reassured him it was unlikely to be anything to worry about and would probably correct itself over time.

Jesse did take a couple of readings but more often forgot. He also forgot about the follow-up appointment and couldn't make another time with that doctor for a further three weeks. This appointment was cancelled by the clinic as the doctor was on unexpected sick leave, and Jesse did not follow up any further at that point. While they were having a significant impact on his health and well-being, Jesse downplayed his ongoing health problems.

***"I see these people who have Long COVID in the news and they are properly ill. I've really got nothing to complain about – I just need to get on with it".***

While Jesse's symptoms of Long COVID are relatively mild, they are having a significant combined impact on his daily life. His lingering fatigue is limiting his participation in both study and community activities and is contributing to general deconditioning. Brain fog is affecting his ability to retain new information and stay connected with his friends and previously enjoyed activities. The impact of his symptoms lies in their subtlety; they do not present as obviously as acute COVID-19 symptoms but persistently erode his ability to function.

***"I know it's only a little thing, but I forget to take my wallet with me to the shops ... I would never have done that before".***

## Current Situation

Jesse feels his energy levels have improved slightly over the past month but are still far below usual for him. He experiences headaches daily, and the painkillers he takes to treat them

are causing him constipation. Jesse reports he has episodes of dizziness that come and go and are often accompanied by palpitations. According to his smartwatch, his average resting heartbeat is 110 beats per minute, although it varies over the course of the day between 50 and 160 beats per minute. He has not taken any further blood pressure readings, as he believes that should have fixed itself by now.

Jesse's grade has declined from an average of 76% to 58% and he is now in danger of failing one of his university units. He is no longer taking on hospitality work, as this depletes his already limited energy levels to the point where he cannot study. As a result, Jesse has been using his credit card to cover energy bills and his rent but is nearing his maximum limit. Apart from university classes and shopping, he rarely leaves the apartment for social activities as they leave him exhausted.

***"I'm just hanging in there ... just keeping my head above water. I might look OK to everyone, but I'm not".***

## Life Roles

Jesse is disappointed and dismayed at his current performance in life roles. All these roles have been disrupted, and some have been lost altogether. His inability to do the activities he previously took for granted leaves him feeling flat and demotivated, and he can't see how to change things for the better.

***"Nothing works ... I want to get back to what I was doing before, but the less I do the less I want to do".***

Role	Before COVID-19	Currently
Worker	Jesse worked casually at the university union bar, between 10 and 16 hours per week.	Jesse has not taken up a shift for the past three months and doubts he will be offered any in the future.
Home Maintainer	Jesse shared household tasks with his flatmates and completed them all independently.	Jesse does very few household tasks, and the apartment is often messy. The flatmate he is friends with is very understanding, but this is causing conflict with the other flatmate.
Friend	Jesse had a wide social network, maintaining friendships with people from various stages of his life.	Jesse has lost touch with many of his friends outside of his university peers, as he is no longer seeing them socially. He is also seeing his university friends far less frequently.
Family Member	Jesse was in daily contact with his family by phone and weekly face-to-face. He also had regular online contact with family online.	Jesse maintains contact with all his family members but is visiting his family face-to-face less often. He has also experienced some conflict with his father, who does not understand why he is doing less with his life now.
Informal Organisation Member	Jesse was a member of the university gym and the local swimming baths.	Jesse has let his gym membership lapse but continues to visit the baths irregularly as he finds swimming relaxing.
Caregiver	Jesse occasionally helped his mother with household tasks when at the family home. No other caregiving duties.	Jesse no longer helps his mother when at the family home or undertakes any other caregiving duties.
Community Member	Jesse socialised in bars and clubs with his friends at least once a week. He also attended most Melbourne Victory matches during the A-League season.	Jesse feels he has withdrawn from the community and is now 'a bit of a hermit' in his apartment.

## Activities of Daily Living

Some of Jesse's activities of daily living have changed a lot since he acquired COVID-19, while he has been able to maintain his participation in others.

***"I can do the basics, and I know it's important that I keep looking after myself."***



An interactive H5P element has been excluded from this version of the text. You can view it online

here:

<https://bercollective.caul.edu.au/enabling-optimising-recovery-covid-19/?p=1396#h5p-47>

**Getting the housework done.** Photo by [Karolina Grabowska](#) from [Pexels](#) / **Back out and about.** Photo by [Keira Burton](#) from [Pexels](#) / **Dating.** Photo by [Keira Burton](#) from [Pexels](#).

Activity	Before COVID-19	Currently
Showering / Bathing	Independent. The apartment only has a shower cubicle.	Independent, but keeps bathing short as he is concerned about getting dizzy in the shower.
Toileting	Independent.	Independent.
Walking / Moving Around	Independent. Able to walk any distance required at a steady pace.	Independent. Able to walk any distance required at a steady pace, however, begins to fatigue after about 10 minutes.
Dressing	Independent.	Independent.
Driving / Public Transport	Independent using public transport. Does not have a car.	Independently, but somewhat limited by available energy levels and other symptoms.
Safety / Emergency Management	Independent.	Independent.
Meal Preparation	Independent, and shared this activity with flatmates.	Independent, but relies on flatmates to make fresh meals cooked from recipes. Provides flatmates with ready meals when it is his turn to 'cook'.
Shopping	Independent, and shared this activity with flatmates.	Independent, but has transitioned to online shopping and delivery only. Jesse has not visited the market for the past three months.
Money Management	Independent and able to manage within a tight budget.	Independent for bill paying, but unable to budget sustainably on a reduced income.
Community Participation	Independent and able to access all local facilities.	Independent and able to access all local facilities. Limited by available energy levels and other symptoms.
Rest / Sleep	Independent. Jesse regularly attained 8 hours of restful sleep per night.	Independent, however, Jesse often experiences broken or shortened sleep (approximately 6 hours per night). He naps in the late afternoon 2-3 days per week but these rests don't have an appreciable impact on his fatigue.



Caring for others	Independent.	Independent, but not currently required to do these activities.
Play / Leisure	Independently participated in physical recreation (gym and swimming), social activities and regularly attended Melbourne Victory matches.	Occasionally goes to a local pub with university friends after classes but is no longer visiting venues at night. Jesse has not attended any Victory matches so far this season.

## Jesse's Goals

Jesse wants to urgently improve his performance at university and return to casual work to improve his financial situation. He would like help with the following goals (but is yet to prioritise them):

1. Get rid of the brain fog so his grades can improve.
2. Return to his previous casual job or get a new job and start earning more money.
3. Going out more often with friends, attending more social events, and getting back to visiting his family once a week.
4. Doing his fair share of the housework in the apartment.
5. Find a new partner.

***"I should be in the prime of my life ... this isn't what I had in mind."***

*What does the evidence say?*

**The risk factors related to contracting COVID-19 and developing Long COVID are complex.**

- While older people have a higher risk of poor outcomes from COVID-19 infection<sup>1</sup>, younger people may be more likely to contract the virus due to their generally more sociable lifestyles, especially following the relaxation of public health measures<sup>2</sup>
- People from Culturally and Linguistically Diverse communities experienced health inequality even before the pandemic, and are frequently marginalised from research and public health initiatives<sup>3</sup>. Along with the impact of

1. Pijls, B.G., Jolani, S., Atherley, A.E., Derckx, R.T., Dijkstra, J.I., Franssen, G.H., Hendriks, S., Richters, A., Venemans-Jellema, A., Zalpuri, S., & Zeegers, M.P. (2021). Demographic risk factors for COVID-19 infection, severity, ICU admission and death: a meta-analysis of 59 studies. *BMJ Open*, 11.
2. Australian Government. (2023). COVID-19 Australia: Epidemiology Report 79. Communicable Disease Intelligence, 47, <https://doi.org/10.33321/cdi.2023.47.72>.
3. Gibbs, L., Thomas, A.J., Coelho, A., al-Qassas, A., Block, K., Meagher, N., Eisa, L., FLETCHER-LARTEY, S.M., Ke, T., Kerr, P., Kwong, E.J., MacDougall, C., Malith, D., Marinkovic Chavez, K., Osborne, D., Price, D.J., Shearer, F.M., Stoové, M., Young, K.R., Zhang, Y., Gibney, K.B., & Hellard, M. (2023). Inclusion of Cultural and Linguistic Diversity in COVID-19 Public Health Research: Research Design Adaptations to Seek Different Perspectives in Victoria, Australia. *International Journal of Environmental*

racism and other systematic inequalities, these factors can contribute to the higher risks of both COVID-19 and Long COVID experiences by people from CALD communities[Shabnam, S., Razieh, C., Dambha-Miller, H., Yates, T., Gillies, C., Chudasama, Y.V., Pareek, M., Banerjee, A., Kawachi, I., Lacey, B., Morris, E., White, M., Zaccardi, F., Khunti, K., & Islam, N. (2022). Socioeconomic inequalities of Long COVID: findings from a population-based survey in the United Kingdom. *medRxiv*.]

**Persistent cardiac and dysautonomia are frequently reported by young adults following COVID-19 infection.**

- In the months following COVID-19, around a quarter of people are diagnosed with a new cardiac condition<sup>4</sup>, most commonly hypertension (20%), tachycardia (24%) and Postural Orthostatic Tachycardia Syndrome or POTS (13%). All of these conditions can have a serious impact on longer-term health, and require monitoring and/or active treatment.
- However, young men (particularly those from

Research and Public Health, 20.

4. Ogungbe, O., Gilotra, N.A., Davidson, P.M., Farley, J.E., Dennison Himmelfarb, C.R., Post, W.S., & Commodore-Mensah, Y. (2022). Cardiac postacute sequelae symptoms of SARS-CoV-2 in community-dwelling adults: cross-sectional study. *Open Heart*, 9

CALD communities) are much less likely to visit their general practitioner or engage in regular health monitoring<sup>5</sup>, putting them at much higher risk of the progression of undetected problems and late presentation for care.

**Persistent headaches arising from Long COVID have a significant impact on health, well-being and quality of life.**

- Chronic headache is the most common neurological symptom of Long COVID, and is thought to arise from persistent inflammation and abnormal metabolism of neurotransmitters<sup>6</sup>.
- Persistent headaches have a significant, but often under-recognised impact on quality of life and function. These symptoms can directly impact quality of life and also exert an indirect impact through the development of depression and its impact on engagement in daily life<sup>7</sup>. For

5. Leone, J., Rovito, M., & Gray, K. (2021). Practical strategies for improving men's health: Maximising the patient-provider encounter. *International Journal of Men's Social and Community Health*, 4(1), e1-e16.
6. Foo, S., Chen, W., Jung, K., Azamor, T., Choi, U.Y., Zhang, P., Comhair, S.A., Erzurum, S.C., Jehi, L.E., & Jung, J.U. (2023). Immunometabolic rewiring in long COVID patients with chronic headache. *bioRxiv*.
7. Kim, S., & Park, S. (2014). The role of headache chronicity among predictors contributing to quality of life in patients with migraine: a hospital-based study. *The Journal of*

example, the loss of workplace productivity attributed to headaches is greater than that caused by absenteeism<sup>8</sup>.

- The secondary issue of constipation Jess is experiencing from his painkiller use will also have a compounding negative impact on his health, well-being and quality of life. However, the provision of education about this condition and its management has been found to decrease symptom severity and increase quality of life<sup>9</sup>.

Headache and Pain, 15, 68 - 68.

8. Simic, S., Rabi-Žikić, T., Villar, J.R., Calvo-Rolle, J.L., Simić, D., & Simic, S.D. (2020). Impact of Individual Headache Types on the Work and Work Efficiency of Headache Sufferers. *International Journal of Environmental Research and Public Health*, 17.
9. Ozturk, M.H., & Kilic, S.P. (2019). Effective of education on quality of life and constipation severity in patients with primary constipation. *Patient education and counseling*, 102 2, 316-323 .