

Long Covid Enquiry

Long Covid - Lyme disease - Lack of support

I am 61 years of age I now work from home as a counsellor, I was previously a self-employed public speaker. I have some pre-existing conditions that are yet to be proven as to whether or not they have contributed to my having Long Covid Symptoms.

History:

Before contracting Covid in July 2022, I was very fit exercise-wise. Walking 3 Kilometres daily in the morning, doing 20mins of Yoga daily and including an afternoon walk for about 2 Kilometres some days. I am also an avid Snow Skier and hiker and have been skiing at an advanced level for over 50 years.

Pre-Existing Conditions.

1. **Recovered from Lyme-induced ME/CFS** in 1992-1994 Clinically diagnosed and treated by _____ in 1995. I have had no recurrence of Lyme symptoms since 1994.
2. **Breast Cancer** October 2019 treated by lumpectomy, radiotherapy and Letrozole tablets ongoing.
3. Early onset **Osteoporosis** as a result of radiotherapy and my cancer preventative medication Letrozole. I am on Prolia injections to help with bone breakage.
4. **Hypotension** - low resting heart rate between 53 - 63.
5. **Irritable bowel syndrome and reflux**
6. **Arthritis** brought on by my Cancer meds that are acute in two injuries in my neck and lower back.

Avoiding Infection:

Due to all the pre-existing conditions above, my husband and I went to a lot of trouble to avoid getting covid as I feared that the potential risk of Long Covid on top of the side effects of my medication, and my pre-existing conditions might mean that I might have to fight another illness on top of everything else.

I had only just recovered from the treatment for breast cancer and during the beginning of covid was still immunocompromised after radiotherapy. I avoided crowds, changed my career so that I could work online from home, and lost a lot of income as a speaker in schools due to the lockdown and wanting to avoid getting covid from school assemblies.

Getting Covid

I contracted Covid19 on the 20th of July 2022, testing positive via a RAT and a PCR on the 21st of July 2022. I didn't attend hospital but was bedridden for 5 days and out of isolation after 10 days on testing neg on a RAT. I was feeling better with just a residual phlegmy cough by day 6 continuing to improve to day 10.

Symptoms included acute fatigue, a deep phlegmy cough, and headache. Some early aches and pains, no fever. After 5 days in bed, I started to improve on days 6 and 7.

Acute Covid Symptoms

I Left isolation on day 10, as I was still showing a positive RAT. On day 12 after feeling quite well, I nearly fainted after a walk to my local cafe.

Post Acute Stage Covid Symptoms

I then started developing a constant dull headache, fainting spells on standing, dizziness and brain fog so bad I had to lie down. During my regular morning walks, I felt like I did when I was having radiation treatment, very slow, woozy and unsteady on my feet. This was frightening and confusing. The symptoms I have with LC are very similar to the ones I had for Lyme 30 years ago but not as bad and debilitating as the Lyme symptoms in 1992 when I was bedridden at times.

Antivirals

I was not eligible for antiviral treatment. None of my pre-existing conditions allowed me to have an antiviral prescription to help protect me with a less acute case of Covid. My Dr refused to write me a script as she said she was not allowed to at the time.

My Long Covid Symptoms are:

1. Headaches particularly in the morning and when tired.
2. Fainting - dizziness when standing and sometimes when sitting or lying down - possible Orthostatic Hypotension not apparent before Covid infection.
3. Brain fog sometimes all day, but particularly around 2.30 pm after a few hours of work or concentration.
4. Cognitive issues. Memory loss, loss of words. Confusion, and difficulty expressing myself clearly. Lack of concentration.
5. Coordination issues during brain fog, typing is difficult.
6. Heavy pressure in my head with brain fog and headaches.
7. Heart palpitations when I lie down, particularly at night with a strong thumping heartbeat.
8. Hot flushes - I am post-menopausal and was no longer getting flushes.
9. Fatigue after moving/exercise, requiring lying down for 30mins to an

hour.

10. Sensitivity to light and sound. Loud noises can hurt.
11. Increasing Joint pain from my back and neck injury.
12. Some breathlessness when tired.

A Long Covid Clinic

I contacted my GP after I nearly fainted, she tested my reflexes, took my blood pressure and sent me for blood tests. All came back fine. No action was taken but she recommended that I could join a local new Govt Funded "Long Covid Rehab Clinic" Which would include "Graded Exercise" with an exercise physiologist a Dietitian and an occupational therapist. I started attending these sessions on Zoom. As I am not deconditioned the rehab is not as necessary. My dizziness and cognitive decline is likely connected to a possibility of PoTS or Orthostatic Hypotension, it seems my autonomic nervous system has been compromised, according to my Cardiologist. More tests are being completed.

Further Testing

My cardiologist has recommended a blood test for Cortisol levels, an MRI of my Brain and a Tilt Table Test to test my cardiovascular system. Fortunately, my cardiologist is very informed about the links between the cardiovascular system and Covid19 infection leading to post covid illness.

A Long Covid Facebook Support Group

I joined a Long Covid patient-run support group on Facebook in the first week of my symptoms, and have found that it has been the most informative resource so far with helpful support from other L.C sufferers. This is run by Long Covid patients some of whom have had long Covid since 2020.

Emotional support and advocacy

The members of this group offer emotional support to help people with LC to keep going, they also help with sharing the latest research papers or recommending resources and Long Covid-friendly medical facilities. As a group, we are signing petitions to get anti-virals listed on the PBS to prevent worsening symptoms, and sending letters and other petitions to Govt to get support.

Good and "Bad" Dr's

Within the support group, there is growing awareness of doctors that don't "Believe" in Long Covid, or who suggest you just rest or attempt graded exercise (which is now not recommended for people with Long Covid, as it exacerbates some symptoms). These warnings and reviews of clinics and practitioners are passed around the group to prevent people from being traumatised by a "bad" Dr or to prevent them from wasting their limited resources and energy seeing a Dr who won't help. The added trauma of seeing a Dr who infers that it's only psychological or who dismisses an LC patient out of hand is debilitating and can cause great distress. Some members write to the group after such sessions in tears begging for support to keep going.

Well Informed Patients

Some Drs need to consider that many people with L.C can be in some ways more informed about legitimate peer-reviewed L.C research than they are. Patients are desperately looking for help and are reading research that is only meant for medical professionals, in an effort to find help for themselves as they are being unsupported or patronised by some medical professionals. Patients are also often self-diagnosing as the help they need is not available.

Some in the community report that this awareness sometimes doesn't go down well with some in the medical profession who can be rude if a patient suggests a referral or asks about medication that might help.

There are also lists in this support group of doctors and other health professionals who are knowledgeable or sympathetic to people with Long Covid, but there are often months-long waiting lists for these rare doctors as they are highly sought after and rare. I was incredibly fortunate to be referred to a cardiologist who took my concerns and symptoms seriously and was someone I didn't have to push for referrals or further testing. This is apparently unusual.

Long Covid Medical Clinics Hard To Find

Recommendations of Long Covid Medical Clinics are shared around, but many have 3-month waiting lists to get in. Some states have none at all. There is confusion about what some of these clinics are supposed to help with. Is it a "rehab" style clinic or a clinic attached to a hospital that will diagnose, test and refer to specialists? Some clinics have doctors who have been reported to be so brutal in their treatment of LC patients dismissing their concerns and telling them to go home and wait for it to all clear up, that people are avoiding them. There doesn't seem to be a "standard" for these clinics it's all ad hoc and so variable in quality.

Crowd Sourced Therapy and Medical Treatment

This type of crowd-sourced therapy and medical advice is happening within a vacuum of proper programs and recommendations or referrals from GPs or other medical professionals. Waiting lists are long for LC-friendly GP's, Cardiologists or Neurologists. Diets are recommended, advice on supplements, breathing, meditation, therapy, psychological help and more. Some recommendations will be a total waste of money and energy and some will hit the mark. It's all experimental and frightening.

There is frustration amongst group members at the lack of informed treatment, Drs who give up on patients, who say they can't treat a patient, or they just don't know where to send a person with Long Covid. Advice given that goes against the recent research coming from respected institutions. And many LC patients simply not being believed by Dr's that they have any physiological illness at all. "It Is All In Their Head"

All of this alongside very sick and exhausted Long Covid sufferers who are trying to advocate for themselves sometimes in an environment of scepticism where they feel that they are being told to just stay home to protect themselves. Long Covid sufferers feel marginalised, hidden, and ignored. After all, Covid is "over" we are a constant reminder that it isn't.

Financial Loss

The other topic of conversation in this Long Covid support group is the Governments unwillingness to financially support Long Covid patients who have had to quit work due to the inability to do their job, or drastically scale back their work. This might also be after already losing income due to lockdown previously, which is the case for me.

Cognitive degeneration can prevent people with LC from doing their job, and the fatigue can render them unable to sustain any employment, some are bedridden or wheelchair bound. Many are digging into savings, and superannuation or are at risk of poverty. Many people with Long Covid have lost their life savings and income. Some might have had pre-existing conditions that already rendered them part-time workers and now they are even more disadvantaged. They are having to pay out huge amounts of money for treatment and supplements that may or may not help relieve symptoms whilst shopping around for doctors who can do something.

Some people are going on JobSeeker with a doctor's letter to say they don't have to complete mutual obligations as they are incapable of work. Recommendations are going around the group on how to get these letters as they don't qualify for NDIS or Disability support.

Unsupported

As a result, many people in this LC support group feel as if they are slowly dying in isolation and risking poverty and that no one cares. We are being put in the "Too Hard" basket and being told to "Protect Ourselves"

All the while it seems Governments are winding back all sensible restrictions like isolation and masks, resulting in most of us being locked in our houses to avoid further infection with covid or flu/cold, as getting another illness again on top of our LC will likely make us all much worse. We are effectively immunocompromised and disabled but not recognised as such and therefore receiving no targeted appropriate support.

My Income loss:

I have lost almost all my income due to covid19, 90% of it.

I was treated for Cancer in late 2019 and had to take 5 months off work for recovery before Covid hit Australia in early 2020. Lockdown coincidentally cancelled my first day back at work which was a full school presentation face-

to-face. I then lost almost all my work over the lockdowns and as a result, I retrained as a counsellor where I can work on zoom from home without risk of catching covid or having more presentations cancelled. I received Covid payments for lost income until they ceased last year.

My loss in income was in fact from Oct 2019, first for Breast Cancer treatment and recovery, for which we had no financial support available for my loss of income. As a self-employed part-time worker, I still don't have income protection, and as a full-time mum of 4, I had very little superannuation and I took it all out when Covid shut down all my work.

Now with Long Covid, I have to cut down my work to just a few counselling clients a week, due to fatigue and other symptoms. Even counselling on Zoom is exhausting. I don't want to go onto JobSeeker as I can still work a little, and don't know if I could receive JobSeeker as I don't want to apply for work I cannot do. I don't have superannuation or income protection.

My husband and I have been living on one income for the last 3 years, with still two dependents living at home.

My Experience With Health Professionals

At my first appointment made after I started getting further symptoms beyond the acute stage of Covid, My GP said that she could not offer medical help for my condition, she had not been given any recommendations from any health department for patients with Long Covid, beyond ruling out any other illness via scans and blood tests. She was however sympathetic and believes I have post covid illness, but won't diagnose me with Long Covid until Oct 21st when I am 3 months post covid infection as per the WHO recommendations. I however insisted on a referral to a cardiologist due to my fainting and the odd heart issues I was experiencing. She also sent me for blood tests to rule out anything else. There are no blood tests for Long Covid.

I have just seen a cardiologist, who has diagnosed me with possible Orthostatic Hypotension which may have been exacerbated by Covid19. She has referred me to St Vincents Long Covid Clinic where there may be a 3-month wait. I have also been referred for more blood tests and an MRI. None of the symptoms I have were apparent before infection with Covid, except for when I was clinically diagnosed with Lyme disease brought on by a tick bite in 1992.

Confusion of Long Covid Diagnosis

There is confusion as to when you can be diagnosed with LC. The CDC in the U.S sets a Long Covid diagnosis benchmark of a month after covid or any ongoing symptoms beyond the acute phase, the WHO says 3 months after the Acute stage. Researchers are suggesting the sooner you have a diagnosis and some treatment, even if it's just lifestyle changes such as pacing and increasing water intake, you will have a better chance of recovery.

Crowd Sourcing Treatments

My experience with treatment and diagnosis has been frustrating because I have had to rely on "crowd-sourcing" for information about my treatment options from the Facebook Long Covid Group. My Dr is not up to date with treatment options. She didn't know for example that graded exercise is no longer recommended for LC. She didn't refer me to a Cardiologist despite me having heart palpitations, dizziness and fainting, I had to insist on a referral. She might have referred me to a neurologist to check out my "brain fog" fatigue and confusion, but she thought I might still be recovering from Acute Covid. She is hindered by a lack of information. There is a risk that If I had followed my GP's advice I may have gotten worse and may have suffered a serious injury.

Post Viral Chronic Illness Lyme and Long Covid.

When I started to see some mention among researchers about other viral chronic illnesses such as Epstein Barr and Lyme reigniting symptoms after a Covid19 infection, I decided to try some of the things I was doing back in the 90s to get well. I have adjusted my diet and am taking similar supplements to the ones I had when I had Lyme-induced CF.

See this link to information about other chronic illnesses that could be reignited after a covid infection. <https://www.scientificamerican.com/article/covid-long-haulers-are-calling-attention-to-chronic-illnesses/> And This <https://livlymefoundation.org/conference/summit-videos/?fbclid=IwAR3Vd2J9ifxdSFRWon-z9QH7y1IPHleTLoyKpMFJZBTwsHjkzyAGCop3Mq4>

My Treatment

I am now on a handful of pills a day, including my preventative medications for cancer, an SRI to help with depression and arthritis that the Letrozole unfortunately causes, Magnesium for muscle cramps, Selenium, Probiotics, Vitamin B, Vitamin D for my Osteoporosis and Osteo Panadol to help me sleep and deal with the pain.

I am drinking 3 litres of water a day with some Electrolytes to help with the dizziness and palpitations. And am "pacing" my energy and resting and eating a low sugar, low lactose diet. I don't drink Alcohol and normally eat a Mediterranean diet.

I feel better than I did in the early weeks and am slowly gaining more energy, but I have to pace and stick with my regime. And stay away from any other infection which could worsen my symptoms.

Social Isolation

I am terrified of getting Covid again, and this means that socially I'm isolated. I can't cope in crowds. I mask everywhere. My family are very careful to protect me. I'm aware that if I get the flu or cold, or another infection of Covid19 my risk

of further disability is very likely. I feel as if I'm in a never-ending cycle of lockdown and isolation, first with cancer, Covid and now with Long Covid. I'm in a constant state of fear and anxiety, and dealing with friends and family who suffer alongside me as they are also compromised by my illness and caution.

The overwhelming behaviour of people in Australia is that Covid is over, but for me and others with vulnerabilities or Long Covid, that means, no eating out, no parties, concerts or crowds of any kind indoor or out, shopping always with a mask and socially distancing. Seeing the hairdresser masked...the optometrist masked. There will not be any relaxation of masking, social distancing, or sanitising for anyone with Long Covid. It was better when the entire population were protective.

There is so much sadness and anger amongst the community with underlying conditions that our "freedoms" have been taken away so that others can do what we would dearly love to do, and could do with some consideration. We are being told to "protect ourselves" in a situation where it is almost impossible to do so without the greater community helping to protect us also. Many are telling us to just stay home. In any other situation, this type of behaviour would be considered cruel and discriminatory, taking away our basic human rights. It seems that this lack of empathy and clear discrimination against the vulnerable is now considered acceptable by our leaders and the population to protect the community who are fed up with Covid and to protect the economy. We are fed up too!

Antivirals Cost \$1000.00

Antivirals help with Acute Covid illness, and those that are vulnerable to serious illness can have them prescribed under the existing PBS. Many people with L.C are not eligible for antivirals, as they don't fit within the existing prerequisites for cover under the PBS. However Doctors have the discretion to prescribe anti-virals to vulnerable people, but if the patient does not fit within the PBS guidelines they have to pay the full price of \$1000.00 per 5-day treatment. This is despite research now showing that repeated infection of Covid19 can worsen Long Covid Symptoms https://www.gavi.org/vaccineswork/new-survey-suggests-reinfection-worsens-long-covid?fbclid=IwAR0IFKWR6RZUNHU6B-sKZYJyOZq_kiMjmX2nnvOlpxz3LvUZKuDGNhKQFVM.

As a fall back I have a prescription for Paxlovid, but if I fill it, I'm not entitled to cover under the PBS, as I'm under 70, not diagnosed as disabled and not considered immunocompromised I will have to pay \$1000.00. This is money I will have to find on credit, but if my health deteriorates as a result of unprotected reinfection I will lose much more than that.

What does The Long Covid Community need?

The main issues for the LC community as I see it are:

1. Lack of medical and Government recognition of vulnerability and

- disability
2. Recognition of increased health risks if reinfected with Covid or another virus
 3. Lack of protections against reinfection - antivirals - community masking - social distancing - air quality considerations.
 4. Forced Isolation to protect from re-infection - social isolation - loneliness
 5. Financial loss due to loss of income and costs of health care
 6. Lack of government financial support for Long Covid patients
 7. A Medical vacuum - not enough medical support or L.C awareness by GPs
 8. Lack of Long Covid clinics and L.C educated therapists
 9. Limited resources for support therapies
 10. Lack of awareness in the community about L.C risks and vulnerabilities
 11. Lack of support from employers who are unaware of L.C
 12. Difficulties with family support due to the impacts on family and sometimes disbelief of illness
 13. Mental health issues - Anxiety and depression due to illness and lack of support
 14. Risks of self-harm due to hopelessness and physical pain.
 15. Frustration at not being helped now or in the past.
 16. Lack of energy and health to be able to fight for our rights and our lives.
 17. Overall Loss of human rights

In Closing

There is an enormous amount of grief for lives lost, financial poverty, and hopelessness in the Long Covid patient community. Some people are recovering, but some are getting worse or not improving. There are doctors who don't know the new findings on LC, and who are recommending harmful treatments or turning patients away.

And all the time, the Government and media are acting as if covid is over. People with Long Covid are being left to manage on their own without the energy or health to do so. Long Covid sufferers feel that the Australian Federal and Local Government and the medical profession are letting us all down, by taking away the restrictions like masks and social distancing. We fear we will be in a self-imposed lockdown for a long time.

I'm hopeful that this enquiry helps to change these issues we face. It is unknown how long we will be sick, and if some of us will ever be as we were before covid. Right now we need a clear finding of disability and vulnerability to qualify for support and medical help and ongoing financial support. These considerations are not something that requires years of research or findings. Not having disability and financial support pushes people with L.C further into despair and poverty and makes it impossible for some to seek treatment.

Many in the Long Covid community are angry that Covid19 was let Rip, and that much of the science about aerosol spread, effective masks and air quality has been ignored. We cannot be protected from further infection and potential worsening of symptoms when we are the only ones with a mask trying to social distance in covid filled air, we will be overwhelmed and therefore have to stay home to survive. Should we quit life to protect ourselves?

We are asking the government of Australia to help and support people with vulnerabilities and Long Covid who don't recover and bounce back from Covid19.

I'm happy to speak with anyone for further clarification of my observations as a lay person with over 30 years of being marginalised due to slow action on chronic illnesses first Lyme now Long Covid.