



Consumers Health
Forum OF Australia

SUBMISSION

**House Standing
Committee on Health,
Aged Care and Sport:
Inquiry into long
COVID and repeated
COVID infections**

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Consumers Health Forum of Australia (2022)
House Standing Committee on Health, Aged
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Repeated COVID infections

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Introduction

The Consumers Health Forum (CHF) thanks the House Standing Committee on Health, Aged Care and Sport for the opportunity to share patient experiences of long COVID and repeated COVID infections.

The consumers who contributed to this submission provided deep insights into their experiences of diagnosis of, and treatment for, long COVID. They used those experiences to make practical and well thought out suggestions to improve understanding of the ongoing effects of their illness and the healthcare services that they need to help them recover.¹

I had COVID for the first time in May this year. My husband's an occupational therapist and he brought it home. I had a relatively mild case – mild symptoms but I was fatigued for a few weeks, before gradually started going back to work.

When I got COVID, I started experiencing cognitive dysfunction – memory problems, executive functioning problems and issues with sound and keeping track of things. It gradually got worse, so I now only work part time.

I picked up another COVID infection about four weeks' ago. My cognitive symptoms got a lot worse. So I went to my GP and I've been put on a waiting list for the long COVID clinic. It's a six month waiting list as far as I know. There's not a lot of help in the meantime.

Nobody really knows what to do. I'm part of a Facebook group, so I try and sort of pick up information from there.

It is clear from their stories that many primary health practitioners do not know how to diagnose or treat long COVID. At the same time, patients can wait many months for referral, and then many more months for treatment, at long COVID clinics. Often, too, treatments are outdated and can exacerbate, rather than relieve, their symptoms.

It's very frustrating to be told that we don't have much long COVID in Australia when no one is really measuring it.

I was in a meeting for long COVID and one of the people worked in one of the local health districts in Sydney said they didn't have a long COVID problem there. We asked, "What do you mean?", and they said that nobody comes forward for treatment. Well, I told them that it doesn't mean you don't have a problem. It just means people either don't know what long COVID is or maybe they're worried about seeking medical care. You know, in this area, people have a lot of problems already.

¹ The direct quotes and experiences of consumers related in the boxes have been edited.

Patient experiences

Stigma, guilt and blame

Some of the health consumers who contributed to this submission had repeated cases of COVID infections that exacerbated their condition. In most cases they were infected either by another member of the household coming into contact with the disease at work, or by a National Disability Insurance Scheme (NDIS) healthcare or support worker.

I'm pretty angry about how it's been treated. I did a lot to try to prevent myself getting infected. I don't go out very much and I mask up in public and I still managed to get it. It's not really a case of being able to protect ourselves when we can't even protect ourselves in our own homes, when there's so much COVID around. So, it's very frustrating to be told to wear a mask to protect yourself when I'm getting COVID at home because there are so many people who have it.

They were at pains to explain how they contracted COVID-19, seemingly because they felt judged, as though they had to justify why it was not their fault. They were also angry and dismayed that they could not evade infection, despite all their care and precautions. They reflected that community attitudes toward COVID-19 were more affected by statements from political leaders and officials, than due to easing restrictions in themselves.

The queue for treatment

There were wide variations in the journey for people with long COVID in accessing, or trying to access, diagnoses and treatment. None of them were quick or uncomplicated, and all were still struggling after many months of debilitating illness.

General practice

The journey for a patient starts with getting a diagnosis and initial treatment by a general practitioner. Long COVID is, increasingly, becoming an area of specialisation for some GPs. A patient may find that their regular GP is either not confident or unwilling to diagnose and treat the condition. Some patients discover practices that specialise in treating long COVID through word of mouth or social media groups. Even so, finding a GP who has developed their knowledge and expertise in long COVID, and can take new patients, can be difficult and is subject to the vagaries of geography.

There are no specialised clinicians and no medical specialty. There is no formal clinical data about us. People are not being seriously looked after, or they are dismissed.

COVID clinics

Likewise, COVID clinics are generally based in major cities and they, too, have long waiting lists. A patient may receive a referral to a COVID clinic if their symptoms persist for at least six months after their infection. Patients who have a clinic in their city report waiting times of around six months until they can access the service.

I'm diabetic and have been isolating for two years, but I do a lot of volunteer work and got COVID – my diabetes went haywire. I lost 7 kg in a week, which should drop sugar levels, but my pancreas has been affected. My endo and GP don't know what's causing this in my usually well managed diabetes.

The quality of care

Issues patients faced included that their regular GP:

- did not accept long COVID as a condition
- did not accept that the symptoms they had were consistent with long COVID
- using outdated clinical guidelines to recommend inappropriate treatment
- being concerned that they did not have the experience or expertise to treat the condition.

It's affected my mental health, and they're so dismissive when I ask about long COVID.

Research and new and emerging treatment

Consumers are often frustrated at the lack of research and trials undertaken in Australia, the inconsistent (and sometimes outdated treatment offered), and access to medications through the PBS that have proven to be effective in overseas trials.

Some of the consumers who spoke to CHF have pre-existing myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). While CHF will not venture into the similarities between the two conditions, patients with ME/CFS can find it difficult to get a long COVID diagnosis precisely because of those similarities.

Long COVID is really troublesome. I am suffering from it since last nine months and I wanted to start my family, but I am very scared. There is no information if it's dangerous for babies, or should I get pregnant while I have long COVID. I checked with my GP and he is clueless. The government is not addressing this issue and I have not seen any translated material on long COVID. Also, I am unsure if long COVID is treated as a disability, because I don't want to be labelled a "disabled person".

The similarities also highlight the variations and inconsistencies in treatments for long COVID. Some practitioners and clinics advise exercise treatments in response to symptoms of fatigue, while others use treatments currently advised for ME/CFS. With such major differences in treatment approaches, it figures that patient outcomes will similarly vary according to the randomness of which GP or clinic they attend.

What [long COVID clinics] do varies based on who's running it and their specialisations. A lot are doing what they were doing for ME/CFS thirty years' ago. They shouldn't be doing graded exercise. It's scary that a young person I know was told they could get well in three months, with such a dangerous treatment.

It is routine for patients to do their own research on new treatments that might help them. Some feel that they have learnt more about long COVID than available at many of the health services available to them.

This is not a new disease. It might've been caused by a different virus, but we know that there are things we can be doing and things to make people better and, in the process, help people with ME/CFS [myalgic encephalomyelitis/chronic fatigue syndrome].

CALD and other disadvantaged communities

CHF has had reports from refugee and other migrant communities with low health literacy that community members do not know about long COVID, so assume their symptoms are reinfections of the disease itself. There is also a great deal of stigma associated with long COVID, which increases community anxiety and ignorance as people avoid talking about the condition.

Long COVID has impacted me and my family a lot. The irony is, as a refugee, I have to prove to everyone that I have a long COVID. Initially my GP was reluctant to acknowledge and later I had to fight at my workplace. I did not ask for compensation or any favour – the least they could do is to respect and understand my health condition.

I have been dealing with the major consequences of this virus for which there is no vaccine nor accepted treatment. It has robbed me virtually of 14 months of my life and there is no real definition of what viruses do once they get into my system. It is more frightening.

I hope to eventually recover and am slowly seeing progress, but the fatigue that I experience has impacted what and how much I can do in my daily life.

Refugees and other migrants with long COVID also report experiencing racism, particularly at work. They are not believed and they may not be given any understanding or flexibility in their workloads or working hours. One migrant said that he works remotely and will not disclose his condition to his employer, or even ask his GP for more information, for fear of having his visa revoked and being deported.

Reports from some communities, particularly in regional areas, suggest that GPs do not tell their patients about the condition, and government and community based organisations that visit and talk to communities do not inform them either. People cannot get diagnoses, followed by treatment and support, if they do not know that they have long COVID.

Other aspects of health and life

Patients experiencing long COVID commonly report increased violence at home, physical and social isolation and mental health issues. Health consumers who were already mostly homebound due to other illness and medical conditions, can experience even greater isolation and loneliness.

I became housebound, surviving in isolation without interaction. I haven't seen my GP for more than 12 months. My support worker got COVID twice, and then her family got it, so I lost the support I need.. Being isolated leaves people open to violence and exploitation.

Consumers who are in paid employment can fear disclosing their condition to their employers, resulting in exacerbating their symptoms.

The way forward

Data measuring the incidence and duration of the effects may not yet be available in Australia, but it is certain that long COVID will have many ongoing effects for the economy, the health system, government payments and supports, and the whole community. Many people are taking long term sick leave or losing their jobs, returning to part time or lower skilled work, or face permanent disability. Those affected by long COVID will have to rely on government payments and health services, will need more paid and unpaid care, and will be unable to fully meet their own responsibilities to provide care for their children and/or others.

The people who are most unwell, those who are bedbound, are the ones who have least access to health care. And that is exacerbated by the face to face requirements [as a prerequisite to telehealth].

Recommendations

An effective response to long COVID requires:

- reducing repeated infections in the community
- earlier treatment and multi-disciplinary care for patients, including mental health needs and other secondary effects, and supports related needs, such as housing, income, family violence
- expanding the reach of specialist clinics and other primary care options that provide consistent, evidence based treatment
- conducting and supporting Australian based research into the condition, while using Australian and overseas research to educate health providers and update treatment guidelines
- improving government (all tiers) community support for people with long COVID and their carers
- increasing awareness of the condition, particularly in Aboriginal and Torres Strait Islander, culturally and linguistically diverse, and other disadvantaged communities, so that people who need it can get advice and treatment.