Submission by Eliza Charley to the Australian Parliamentary Inquiry into Long Covid and Repeat Infection held by the House of Representatives Standing Committee on Health, Aged Care and Sport.

This submission is made in response to Terms of Reference 1, 4 and 6.

Introduction

My name is Eliza Charley. I am an actress, writer, and Australian citizen currently residing in Italy.. I have lived with Myalgic Encephalomyelitis for most of my adult life; my subtype is viral-onset (2009) with post-surgery relapse (2020), and post-vaccine worsening (2021).

During the COVID-19 pandemic, I have been a **health consumer in Australia and Italy**. Additionally,I have received care at a **Long Covid & ME/CFS research clinic in Germany**.

I will be providing a statement of my repeatedly negative experience at the hands of healthcare in Australia, including during this pandemic, and a statement of mixed experiences in Europe.

I would welcome the opportunity to discuss any of these points in further detail.

Please note: While this is a vitally important inquiry specifically into Long Covid and repeated infections, it occurs within a history and context of post-infectious chronic disease in Australia.

This means, many of the factors driving systemic harm (and possible levers for change) have been proposed in related inquiries. This past work has come at great cost to patients living with energy-limiting diseases; often with little to no action resulting from government and health leaders.

Please consider the themes and insights from existing patient-led petitions, expert panel investigations, and reports from not-for-profit organisations. These include:

- **National Health and Medical Research Council (NHMRC)** *“Myalgic Encephalomyelitis (ME/CFS) Advisory Committee Report to the CEO”.* 30 April 2019.
- **Call For Change Australia** (with **Doctors with ME, UK)** *“Petition and Submission to the Australian Parliament and the* ***Disability Royal Commission*** *into Violence, Neglect, Abuse and Exploitation.”* 2022.
- **Emerge Australia** *“State of the Nation: Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), Long Covid and post-infection diseases”* with foreword by Prof. Peter Doherty. 22 March 2022.

Background: Long Covid & ME/CFS

The ‘unexpected’ and ‘unprecedented’ phenomenon that was explicitly predicted by patients and researchers, backed by a 90-year history of documentation and research.

When the SARS-COV-2 virus emerged, it was clear to many of us in the ME community that this latest coronavirus would undoubtedly cause a similar disease in at least some patients. Similar outbreaks were first documented in the 1930s, coined Myalgic Encephalomyelitis (ME) in the UK in the 1950s and named Chronic Fatigue Syndrome (CFS) in the United States in the 1980s (Tate et al, 2022).

Despite statements by ME patients, charities, researchers and even online campaigns such as #StopRestPace, the call to prevent and prepare for a shadow pandemic of chronic disease was not heeded by many leaders - especially not to this overwhelming scale.

Consequently, there are now an estimated 145 million patients globally with specific ongoing sequelae from SARS-COV-2 infection (IHME, 2022), with an estimated 400,000 Australians (The Saturday Paper, 15 July 2022). According to a number of early studies, up to half of Long Covid patients meet the diagnostic requirements for ME/CFS (ME Action, 2022). It is a large and heterogenous group, just as ME/CFS is a large and heterogenous group. There are differences and similarities.

Each number, though, is a real person - with friends and family, hopes and goals, work and community. Every day there is this unabated disease spread, this figure is growing. Every day the current challenge and the future burden is expanding.

Moreover, the evidence is mounting to show repeat infections increase likelihood of Long Covid, such as a new analysis of over 5.3 million health records showing increased short and long term health risks, including Long Covid, regardless of vaccination status (Bowe et al, 2022).

Concurrently, in the case of ME/CFS, we are generally prone to infections to begin with. Repeated challenges to the immune system of any kind can contribute to the progression of the disease. This makes existing in a pandemic with uncontrolled disease spread exceptionally limiting and secluded in our immunocompromised state.

Shockingly, despite the demonstrable deficits and dysfunction in the immune systems of ME/CFS patients, the Australian Technical Advisory Group on Immunisation (ATAGI) persists in specifically excluding ME/CFS from categorisation as immunocompromised. For me personally, my former GP used their specific advice as a reason to refuse me a COVID-19 vaccination in 2021; I had to seek vaccination elsewhere through a state-run clinic in Victoria.

The best time to acknowledge the neglect, count the impact, update the guidelines and advice, educate clinicians and establish appropriate care pathways for such diseases, was well before the current pandemic. The next best time is now. Swift and effective action is needed urgently to address these crises.

Statement of experience: Australia

With more than a decade of lived experience with viral-onset ***Myalgic Encephalomyelitis (ME/CFS),*** I have witnessed the undeserved dismissal, abuse, misdiagnosis and mistreatment of both ME/CFS and Long Covid patients across the globe.

As I type out this submission - mostly written horizontally in bed in my notes app in small windows of cognitive energy - there are too many examples from Australia that come to mind:

- Having a severe worsening of POTS and my (now former) GP laughing in my face, mocking me, and denying I had a previous tilt-table-confirmed case of POTS.
- A naturopath, who gratefully helped me get access to some research-backed testing, yet also told me to “wear more feminine dresses” as part of my treatment.
- Writing to the RACGP to ask about the HANDI guide and receiving an email of condescension and myth-based excuses.
- Being told my disease is everything from ‘sin’ to ‘sickness beliefs’, and yet not one helpful prompt towards appropriate ME researchers, international specialists, or patient-led information that I eventually found on my own and made a difference.

It is my experience and opinion that Australia is one of the worst culprits. This includes pervasive miseducation in the medical system, harmful stereotypes & prejudice, myth-based narratives, negative attitudes and irresponsible excuses designed to pass-the-buck.

Negative attitudes and patient-blaming blocks access to appropriate & adequate care

Research using machine learning technology has revealed **doctors’ attitudes towards ME/CFS are more negative, stigmatised and prejudiced than towards any other chronic disease,** with likely impacts on “decision making, prescribing behaviour, and quality of care” (Scoles et al 2022).

Elsewhere, research shows **medical education plays a key role in teaching and reinforcing these misconceptions,** as demonstrated in an audit of UK hospital doctor’s knowledge of ME (Hng et al, 2021)

It would not be a stretch to expect these poor attitudes and subsequent poor care would extend to **negative outcomes for Long Covid patients too**. Indeed, there have already been examples of this by Australian doctors online, in the media and even in this very inquiry.

Online, one Australian doctor proposed not talking about Long Covid as a means for stopping Long Covid, joining support groups was openly discouraged under some fear that patients would make each other sick, and patients were apparently not meant to rest for fear of ‘deconditioning’; as if the disease was caused by ‘believing’ it or adopting certain ‘behaviours’, rather than due to demonstrated dysfunction and pathophysiology being replicated in studies worldwide.

Meanwhile, state health agencies have been seen encouraging exercise, which can be seriously dangerous for Long Covid patients. And as the personal submissions to this inquiry show, both ME/CFS and Long Covid patients have had a steady stream of psychologisation in public and private during this pandemic, whether that be when seeking medical care or when attempting to shield from infection or reinfection.

In this very inquiry, some woeful statements have been made about Long Covid patients by medical practitioners, even those apparently leading Long Covid clinics.

Examples are not limited to the equating of ‘palpitations’ with ‘anxiety’ (when postural tachycardia is a measurable and known common comorbidity with Long Covid), and labelling patient behaviour as ‘hypervigilant’ rather than understanding the basic principles of pacing and PEM.

These are not new or unique observations, they exist within a long and sordid history of blaming post-infectious chronic disease patients for their own disease, and designing ‘therapies’ for them to ‘heal themselves’; all the while refusing to perform appropriate tests, denying prescriptions for common and measurable comorbidities, and going so far as stating on clinic websites that they outright will not see patients with ME/CFS.

To correct course and build momentum towards fast and important change, there is a need to acknowledge the harms, count the cost, update guidelines, educate clinicians, and establish care pathways.

Australia, where did we go wrong?

The disastrous approach in Australia comes down to this: **There is a focus on behaviour and belief, rather than biology.** These blinkers have become an industry-wide blindspot when it comes to ME/CFS, Long Covid, and related diseases.

As a result, frameworks and treatments have been created based on myths such as ‘deconditioning’ (quickly disproven with a 2-Day CPET test for PEM patients), and on stereotypes such as ‘hysterical women’ and ‘depressed and anxious females’, leading to approaches such as the much-discredited Graded Exercise Therapy (GET) and Cognitive-Behavioural Therapy (CBT).

I myself have experienced the negative impacts (including disease progression and worsening) from such so-called treatments and approaches, including GET, CBT and expensive mind-manipulation courses . The latter is especially insidious as it teaches patients to say they are not sick - to the point of handing out printed pamphlets to friends & family with instructions to not talk about it anymore. Patients are still suffering, but their support network is abruptly stopped.

It is my honest opinion that there is currently no role for any of these manipulative approaches for Long Covid patients, just as they should be banned in Australia for ME/CFS. At the very least, they should not be offered unless proven ‘safe’ for a particular patient, and even then, they should be regulated so that patients can provide informed consent with a reporting mechanism for harms.

Australian clinics, associations and individuals continuing to perform this theatre of “treatment” founded on myth and prejudice, is akin to denying climate change or advertising ‘safer’ cigarettes. It is doing mental and physical damage to countless Australians.

Let's be very clear: So far from being banned in Australia (as they are in other regions, such as the UK NICE 2021 guidelines for ME/CFS), these harmful practices and attitudes are shockingly endorsed in Australian guidelines, clinics, and education. These treatments are not benign and should not be handed out so freely with no thought (or support) for the routine consequences.

Now, with Long Covid, Australian guidelines are repeating the same mistakes. One example, the NSW Health clinical practice guideline made reference to 'females' with 'anxiety' as being a core driver of 'fatigue', while repeatedly encouraging 'aerobic exercise' throughout the piece.

The alternative? Establish and provide access to adequate and appropriate pathways to care. For example, provide clear public health messaging about exercise cautions, encourage psychology for support on the disease journey not for manipulation of beliefs, and update clinical guidelines for both ME/CFS and Long Covid to support this.

It's time Australia came out of the dark ages and aligned with the scientific research community.

Statement of Experience: Italy and Germany

The psychologisation and mistreatment of Long Covid patients and ME/CFS patients is present across the globe. Europe is no exception. However, I have been in a position to access several specialist clinics, met dozens of patients and met with researchers.

Italy - primary care

ME/CFS is not a recognised or taught disease in Italy as far as I'm told; and this does represent a certain problem. However, I have received better and more appropriate medical care in Italy from doctors who have never heard of the disease, than from Australian doctors who are actively taught the wrong thing. Together we have been able to undertake tests and try new medications that have helped my condition. I've received diagnoses for important comorbidities and this affects many aspects of how I can now manage my health and life.

Generally, the primary healthcare system is well set up to support doctors to manage care for complex and chronic conditions. For example, support of clinics appears to be made based on region and number of patients, not on 15-minute billable timeslots. As a consequence, there has not been a problem in having extended time to review results and discuss treatment options.

There has also been an attitude from the outset of setting up regular appointments to ascertain continuity of care, and the primary doctor has been like the conductor of an orchestra, able to coordinate referrals, prescriptions and tests with a number of different disciplines.

Ideally, this is the role of General Practice in Australia. However, this is often not the case for diseases like Long Covid and ME/CFS. I will continue to stand with GPs in Australia and their call for better working conditions to support their important and vital work in the community. It is possible to support their important call for change, while also calling them to account to change their education, guidelines and approach to ME/CFS.

Germany - specialist Long Covid & ME/CFS clinic

Substantial research has been published in the past two years on the pathophysiological pathways and biomedical abnormalities found in patients with Long Covid. There is also more than three decades of biomedical research published on pathways andl abnormalities in ME/CFS. This is good news. This is meaningful for treatment options and it is helpful in countering the false narrative of “There is no pathophysiology”, when indeed there most certainly is - when you are looking in the right place.

In May 2022, I travelled to Mulheim-an-der-Ruhr, Germany, to a clinic undertaking research, running tests and providing treatment for Long Covid, vaccine-injured, ME/CFS and similar patients. There I was greeted with warmth and science - a stark contrast to the pseudo-compassion, dismissal and gaslighting that is ever-present in Australia.

Every clinician, researcher and nurse I encountered had a solid understanding that this was a physical disease, with underlying disease mechanisms, and that even if these weren’t yet fully understood, there were at least some medical treatments available to try.

One such emerging piece of the puzzle is a number of abnormalities in the blood plasma, including amyloid fibrin “microclots” (Kell et all, 2022), hyperactivated platelets and evidence of endothelial damage. Leading researchers in this area include Etheresia Pretorius, Gert Jacobus Laubscher, and Douglas B Kell; their initial findings have been replicated.

My blood tested positive for all three markers on the first day. This meant I was eligible for two streams of initial treatment: (1) “Triple Therapy” - a stack of three anticoagulants, usually Aspirin, Clopidogrel and Heparin or Apixaban; along with a stomach protector, and (2) H.E.L.P Apheresis - a 2-3 hour blood plasma dialysis using a Heparin-based product to filter the blood.

Participating in the treatment on several trips to Germany was difficult, challenging, expensive (crowdfunded) and at times painful. But patients with Long Covid or ME/CFS are some of the strongest people I know.

We are very capable and very willing to do difficult and painful things - especially when there is some evidence it may make a difference; especially when it’s *not* more attempts to gaslight, belittle, deny, or shift responsibility back on the patient to ‘heal themselves.’

Taking a research- and science-based approach to treating the disease means understanding the physical nature of the disease and decidedly moving away from the over-psychologisation of the past. For me, it meant other avenues for testing and treatment also became available. Known comorbidities (e.g. hypoxia, hyperglycemia) , common auto-antibodies, and tests that should be routine for ME/CFS and Long Covid (e.g. EBV reactivation panel), were able to be conducted and medications and treatments prescribed accordingly.

As a consequence, I went from being the sickest I'd ever been to now being able to begin to re-engage with life in a part-time capacity.

At the start of this year, I could barely crawl to the bathroom, I could not be upright for more than 60 seconds, I could not tolerate social visits, and I spent most of my time laying flat on the floor in a darkened room with noise-cancelling headphones.

Now, I am able to sit up for 1-2 hours a day, some days 2-4 hours, I sometimes contribute to cooking, my brain is returning and I've been able to learn new information again and form memories better, I can spend time socially once every 7-10 days, and I can do some seated gardening or drawing on my balcony. I no longer live and sleep on the floor. I can shower more than once a week. I am still an ambulant user of mobility aids, I am still restricted and I am still immunocompromised, but I have some life again.

Still, still I hope. I hope for more treatment options, and I am trying several; I hope for a better quality of life, even while I'm still sick; and I hope to stay safe from Covid infections and other viral infections. I hope that opportunities I've been afforded here can become standard and readily available and accessible everywhere. This is a global crisis.

I hope to see Long Covid clinics and ME/CFS clinics that are multidisciplinary with cardiologists, immunologists, endocrinologists, and haematologists; not CBT-psychologists and GET-exercise physiologists.

But most of all I hope that not one single person in Australia has to go through what I've been through in the last almost 14 years. I hope to see a day where not one single patient sits in the consult room only to be told 'there's nothing wrong with them' when they are clearly outlining the many things that are clearly wrong with them. I hope that no one is prescribed inappropriate and dangerous treatments. I hope that friends and family instantly recognise and support people with this disease. I hope that no one is brushed aside, no one is belittled or minimised, and no one is sent away with nothing, when there is much to offer.

Recommendations

- Start today. Don't delay.: Prevent, Prepare and Proactively provide care.
- Reinstate masks in public places to allow access for disabled and vulnerable people
- Reinstate masks and support ventilation as part of vital workplace safety and workplace accessibility for disabled and vulnerable people, including events and performances.
- Acknowledge SARS-COV-2 is an airborne biohazard that causes disease and disability
- Actively educate and support ventilation strategies to supplement vaccine approaches
- Be proactive and lead the narrative of Long Covid, dispel myths and promote what we do know of the pathophysiology of the disease, especially to help prevent harmful psychologisation & spiritualisation (some religious groups blame chronic disease on sin)
- Act on NHMRC 2019 ME/CFS report recommendation to update RACP clinical guidelines

- Recognise that ME/CFS patients in this pandemic are an immunocompromised group and have this reflected in the ATAGI guidelines.
- Clarify the advice for antivirals and allow broader access so as not to let stock spoil while immunocompromised and vulnerable australians go without treatment for repeat infections
- Call for the removal of the RACGP HANDI guide for Graded Exercise Therapy
- Acknowledge the harms of GET & CBT, Call for end to these practices for Long Covid and ME/CFS. At a minimum, regulate these practices and put mechanisms in place for the reporting and tracking of harms, and for patients to be enabled to provide informed consent.
- Provide adequate and appropriate medical and social services for patients - this includes telehealth and home visits. There are bedbound Australian patients who currently have no access to any healthcare at all.
- Educate a broad range of healthcare providers, including GPs, on appropriate diagnostics and treatment approaches for ME/CFS and post-infectious diseases using reputable, expert consensus guides (e.g. Institute of Medicine 2015, Mayo Clinic Proceedings 2021, ME International Consensus Primer 2012)
- Secure funding for Emerge Australia (ME/CFS organisation)
- Secure funding for Australian-campuses of international biomedical research into ME (e.g. The Open Medicine Foundation, Melbourne campus)
- Produce a protocol for welfare and appropriately train independent assessors in the NDIS
- Acknowledge that Long Covid also affects children and can be severe in children
- Recognise the importance of oral health and dentistry in the impacts and treatment of ME/CFS and Long Covid
- Establish testing pathways for post-infectious chronic disease patients to investigate their history of infection by viral pathogens
- Provide accessible testing & treatment for common Long Covid comorbidities: POTS, MCAS, HEDS, CCI/AAI & spine-related complications, EBV & HHV reactivation, Microclots & Hyperactivated Platelets, hypoxia / Venous Blood oxygen saturation, Chronic Epipharyngitis & Pharyngotonsilitis. And possible comorbidities where relevant, Dysautonomia & related autoimmune diseases (Sjogren’s, Celiac, Hashimotos, RA, Lupus and Antiphospholipid syndrome), Lyme, Bartonella and tick-borne diseases,
- Allow access for specialist testing such as cerebral blood flow, blood volume, and brain scans, 2-Day CPET testing and other relevant insights to disease severity and management.
- Investigate links between GET-providers who allegedly have had undue influence, such as in the assessment of ME/CFS patients in the NDIS, and in the development of Long Covid guidelines, especially in light of alleged conflicts of interest and recently releasde Freedom of Information requests.

Conclusion

The challenges facing leaders during this pandemic are vast and varied. With Long Covid, it must start with prevention of infection and reinfection. Every case is risking long term sickness and incapacitation, and at a time when systems are not yet established to treat on this scale.

Counting cases and treating cases are admirable and important goals. However, Australia is much further behind when it comes to adequately educating and equipping healthcare professionals to diagnose, test, and treat this disease, so that cases may be counted and so that data can be meaningful.

Urgent calls for change in Australia have been in place since well before the pandemic, and they are growing in importance. Changes to attitudes, research funding, medical education and clinical guidelines in the area of post-infectious chronic disease are overdue and the gap is widening. We cannot change the past but we can begin to make much-needed changes today.

Action for Long Covid and ME/CFS matters for every Australian already impacted, but it is also vital for the very-near future. Unmitigated spread of this disease will continue to impact the economic and societal fabric of our nation.

At this scale, the burden of prevention and preparation, cannot be held at the individual level. Coordinated, government-level intervention and leadership is needed.

The opportunity here is that we do have some insight into what the next ten years could look like for Long Covid, by looking at the long term impacts and risks of similar diseases such as ME/CFS.

Accordingly, we can prepare for the knock-on effects and high-risk categories that can reasonably be predicted, and sadly already are being experienced by some Long Covid patients. Groups that work in these areas could be preparing now for an increased need and demand in services:

- Homelessness & housing affordability
- Suicide prevention
- Unemployment and underemployment
- Domestic and family violence
- Medical risks: e.g. Stroke, Heart disease, Dementia, Cancer and Diabetes

Do we know everything definitively about Long Covid and ME/CFS? No.
Do we know enough to stop harming patients and delivering better care today? Yes, absolutely.

Thank you for your time and attention to this matter.

Eliza Charley

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