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The Australian Dysautonomia and Arrhythmia Research Collaborative,  
University of Adelaide

A Submission to the Inquiry into Long-  
COVID and Repeated COVID Infections:  
Postural Orthostatic Tachycardia  
Syndrome and its Association with Long-  
COVID.

Submission to the Standing committee on Health, Aged Care and Sport

November 2022

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### Executive Summary:

As Australia enters its fourth wave of the COVID-19 pandemic, the pressure on our health system is once again in the limelight.

The World Health Organization estimates that approximately 10 to 20% of people experience a variety of mid- and long-term effects after they recover from their initial COVID-19 illness.

Sufferers of Long-COVID often present with a wide range of symptoms including fatigue, shortness of breath, palpitations, chest tightness, nausea & vomiting, diarrhoea, joint or muscle pain, dizziness, cognitive dysfunction, and sleep disturbances that affect activities of daily living as well as work or study capabilities.<sup>1</sup>

**Emerging evidence suggests that a significant proportion of Long-COVID is underpinned by autonomic dysfunction**, a condition that is poorly understood by healthcare providers.<sup>2, 3</sup> Several case studies and observational series have highlighted the high proportion of individuals with Long-COVID demonstrating objective evidence of autonomic dysfunction.<sup>4-6</sup> In a prospective observational study, 96% of those with Long-COVID demonstrate autonomic dysfunction on tilt table testing.<sup>2</sup> Preliminary unpublished data from the University of Adelaide supports these findings which demonstrated **the high prevalence of autonomic dysfunction, specifically, postural orthostatic tachycardia syndrome [POTS] in those with Long-COVID.**

POTS is an autonomic disorder identified by its hallmark manifestation of postural induced rapid heart rate in the absence of blood pressure drop on standing.<sup>7-9</sup> **The syndrome has a high female prevalence (>80%) and appears to mostly affect those of childbearing age.**<sup>8-10</sup> Patients with POTS often experience diverse and multisystemic symptomology with sometimes severe impact on activities of daily living including ability to self-care or engage in education and employment. POTS remains poorly recognized among clinicians with frequent reports of protracted delay in diagnosis.<sup>8, 11</sup>

The American Autonomic Society has released a statement on Long-COVID postural orthostatic tachycardia syndrome (POTS) following increasing reports of POTS diagnosis in those with Long-COVID.<sup>12</sup> **A striking resemblance exists between POTS, and other forms of autonomic dysfunction, and Long-COVID.**

**Post viral autonomic dysfunction is certainly not a new phenomenon, but rather a grossly under recognised condition.** It manifests in multiple disease states and is common amongst those with Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) which frequently manifests after viral assault. Recent evidence demonstrates that ME/CFS patients with autonomic dysfunction manifest more severe disease and significantly worse quality of life than those without.<sup>13</sup> Our clinical experience, suggests that poorly treated autonomic dysfunction in Long-COVID also results in worsening ability to engage in usual activities and precipitates worsening functional decline.

**It is hypothesised that syndromes like POTS/ME/CFS are the result of a secondary immune response rather than a primary response to the virus.** This would explain why those who develop POTS after other viruses unrelated to COVID-19 [and indeed varying vaccines], present with strikingly similar symptom profiles. This would suggest that the similar disorders of POTS/ME/CFS and Long-COVID should be considered as neuroimmune axis, rather than infectious, disorders.

International data demonstrates the immense burden of disability and reduced quality of life exerted on those afflicted with POTS.<sup>14</sup> It is reported that almost 25% of those affected are so disabled that they are unable to work or study. As with Long-COVID, women of child-bearing age are disproportionately affected by this disorder. **This has significant implications for the economic burden to society and the social and economic toll borne by women in this secondary pandemic.**

The burden of POTS is under recognised and 'unseen' by the Australian health sector, primarily due to the absence of a unique international classification of disease code [ICD] in the current iteration [version 10] utilised by Australian health authorities. The Centre for Disease Control [CDC] has recognised the growing burden of POTS and has recently sanctioned the emergency inclusion of a unique ICD code for immediate use in the United States. **Australia remains without a unique code and therefore the burden is untraceable in this country.**

The information we present in this submission comes from both patients with Long-COVID and POTS and demonstrates the difficulty this patient cohort has in accessing timely and appropriate care. Our recommendations are as follows:


- **Urgent and intensive upskilling** of both allied health and medical practitioners to better recognise and treat autonomic disorders.
- **We call for Australia to follow the lead of the United States, by providing an emergency provision for a unique ICD code for POTS into the current 10<sup>th</sup> Edition.** Alternatively, there should be an impetus to move to the 11<sup>th</sup> edition where POTS already has a unique code (8D89.2). This would facilitate appropriate and detailed tracking of the burden of autonomic disorders associated with Long-COVID within the Australian health care system. It would likewise incentivise health care providers and facilities to appropriately treat and manage autonomic disorders.
- **There is an immediate need for a committee to review the MBS, PBS, NDIS and DSP guidelines relating to the provision of support and medical treatment for those with POTS/ME/CFS/Long-COVID.** In particular, there should be appropriate codes and funding to support the use of autonomic testing in the diagnosis. Vasopressor and heart rate medications such as **Midodrine and Ivabradine** should be made available on the PBS to improve the equity of care and treatment of those with autonomic dysfunction.
- **Research funding should be immediately directed towards uncovering the true burden of health utilisation and cost to the economy associated with all environmentally triggered neuroimmune axis disorders.** This funding should be

informed by key community stakeholders from the POTS, ME/CFS and Long-COVID communities. Where possible, patient researchers who understand and experience these conditions should be involved in development of research methodology and implementation of research interventions.

- **Establishment of dedicated autonomic testing facilities in major tertiary health institutions with suitably trained autonomic physicians and allied health professionals to provide multidisciplinary care for sufferers with Long-COVID and similar illness.**
- **Clinical guidelines and access to care for the management of Long-COVID should not be restricted to the viral cause of the syndrome.** This should rather encompass the array of environmentally induced neuroimmune axis disorders such as POTS/ME/CFS and Long-COVID, irrespective of the trigger. Included in this cohort are those who experienced these disorders as a result of varying vaccines and other environmental triggers such as bacterial infection and trauma.

**Nomenclature:** There are several descriptors in the literature to define the persisting symptoms after COVID-19 including 'Long-COVID', 'long haulers', 'post-acute sequelae of COVID-19', 'post-COVID syndrome'. Throughout this document Long-COVID will be referred to as Post-Acute Sequelae of COVID-19 [PASC].

**Definition:** The working definition of PASC throughout this document is based on the World Health Organisation [WHO] Delphi Clinical Case Consensus<sup>15</sup> and the National Institute of Care and Excellence [NICE]<sup>16</sup> definition of post Covid conditions:



## WHO Clinical Case Definition

- Occurs in those with confirmed or probable SARS CoV-2 infection
- Within 3 months from onset of acute infection
- Symptoms that last for at least 2 months
- Cannot be easily explained by an alternative diagnosis.

[https://www.who.int/publications/i/item/WHO-2019-nCoV-Post\\_COVID-19\\_condition-Clinical\\_case\\_definition-2021.1](https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1)

We would like to thank the Minister for Health and Aged Care, the Hon Mark Butler MP for the invitation to submit to this inquiry. Our submission below is founded on the clinical and research experience of the Australian Dysautonomia and Arrhythmia Research Collaborative (ADARC), The University of Adelaide and the Australian POTS Foundation who is working to raise the profile of those with POTS in Australia and fund research into the mechanisms of this disabling condition.

## About

### The Australian Dysautonomia and Arrhythmia Research Collaborative

- is headed by Clinical Professor Dennis Lau who is an electrophysiologist and cardiologist with more than a decade of experience in the field of autonomic research. Professor Lau was a contributing author to the Heart Rhythm Society's international consensus on the management of POTS.<sup>17</sup>
- is the only clinically based, dedicated autonomic research group in Australia. Our group has several publications in this space and are ranked first in 'Expertscape.com', for authorship on POTS in Australia.<sup>8, 9, 17-25</sup>
- holds the only Patient Registry for Postural Orthostatic Tachycardia Syndrome in Australia. We currently have over 500 patients enrolled on this registry.
- has undertaken the only comparative trial exploring autonomic dysfunction in PASC in Australia. [Registered with the Australian New Zealand Clinical Trial Registry]. Our study is now complete and some of the preliminary findings are addressed to the terms of reference below.

### The Australian POTS Foundation

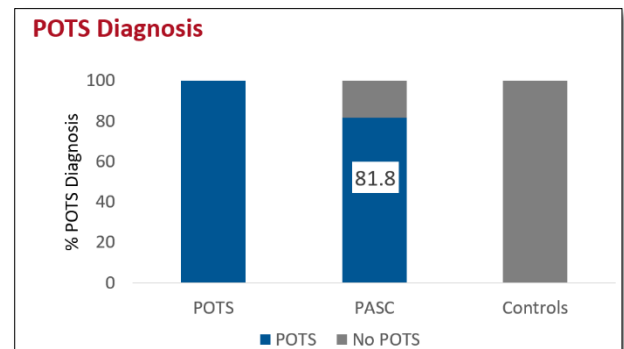
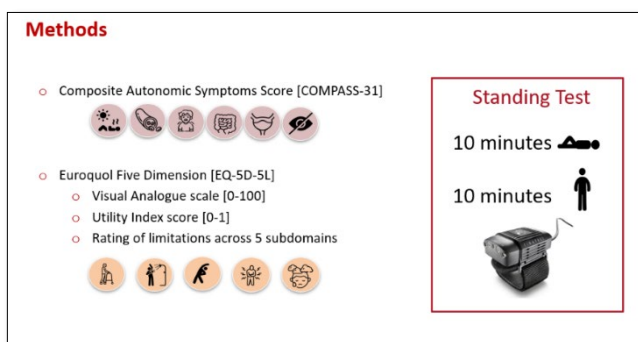
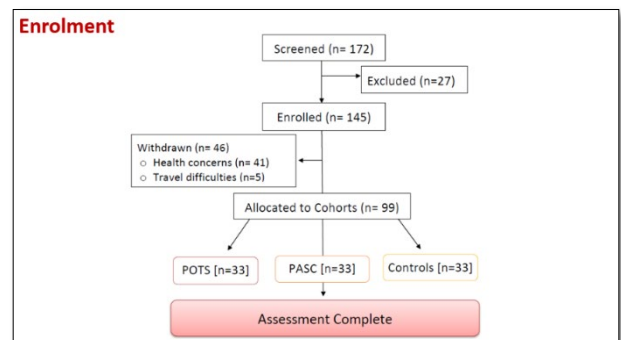
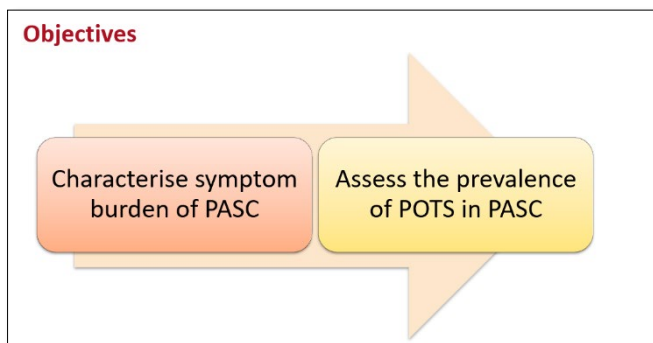
- was established in 2021 and is registered with the Australian Charities and Not for Profit Commission as a charitable organisation.
- was founded for the purposes of raising awareness and funds to facilitate research and improve support for those living with POTS in Australia.
- has recently held the first scientific conference [29<sup>th</sup> October 2022, SAHMRI, Adelaide] to address and educate clinicians on the complexity of autonomic dysfunction and its association with neuroimmune and connective tissue disorders and PASC
- provides the only PhD bursary in Australia for those researching POTS
- supports summer research internships for those researching POTS
- provides free allied health and GP webinars for the management of POTS

## Addressing the Terms of Reference of the Inquiry

### 1. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID in Australia

#### Postural orthostatic tachycardia syndrome (POTS) in Long COVID syndrome: A detailed profiling study

Australian New Zealand Clinical Trials Registry (ANZCTR): 12621000476831

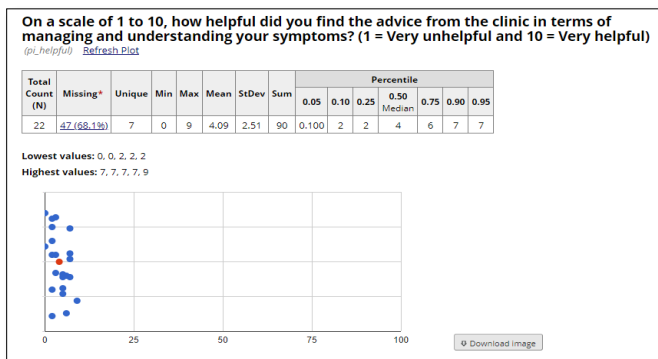


- Our findings from this comparative study demonstrate a high burden of autonomic dysfunction in those with PASC. PASC bears a high similarity with POTS and on most measures is indistinguishable from this syndrome. This supports previous findings that disturbance to the autonomic nervous system triggered by immune responses to Covid-19 are likely responsible for the symptoms manifested in PASC.
- Our study is continuing to recruit PASC patients. The continuing analysis remains commensurate with our preliminary findings, and we are confident from our experience that this condition involves multi-system autonomic dysfunction that, when managed appropriately, results in improved functionality and quality of life.

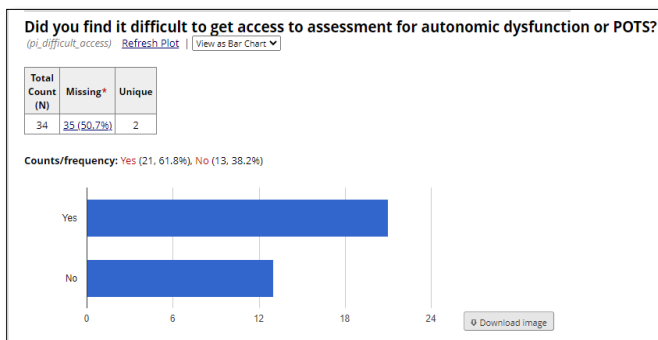
## 2. Our experience as healthcare providers in supporting patients with PASC

Our expertise:

- As the only multi-disciplinary service dedicated to the assessment of POTS in Australia. This centre is privately based due to the lack of funding through the public health system for this condition.
- Our clinic currently sees more than 600 patients with autonomic dysfunction and receives approximately 15-20 new referrals a week. Currently around half of these are for those with autonomic symptoms post COVID-19 infection.
- The Australian POTS Foundation undertook a small survey via social media recently. The only state not represented in responses was Western Australia. The anonymous survey represented responses from 70 individuals with PASC. Of these, around 30% had been refused an appointment at a long-COVID clinic despite their ongoing symptoms. 58% had been diagnosed with POTS, and 70% of these stated that their diagnosis was difficult to obtain. 60% stated they had to tell their doctor how to test for it.
- Respondents completed the Composite Autonomic Symptom Score (COMPASS-31). All but three of the 70 scored >16 suggestive of at least a moderate degree of autonomic dysfunction.
- The following responses reflect the daily experiences that are detailed to us by our community. Anecdotally, we frequently see patients who had been seen at a public long-COVID clinic without receiving a diagnosis, or indeed undertaking any testing for autonomic dysfunction, despite clear symptomatology suggestive of POTS.

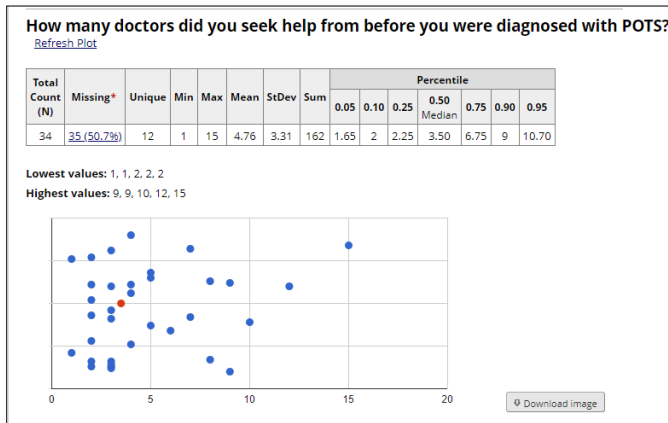


• Patient's repeatedly report limited usefulness in attendance at Long-COVID clinics (average score 4.1 out of 10). We believe this is due to the lack of awareness in these clinics on how to assess and care for autonomic disorders.

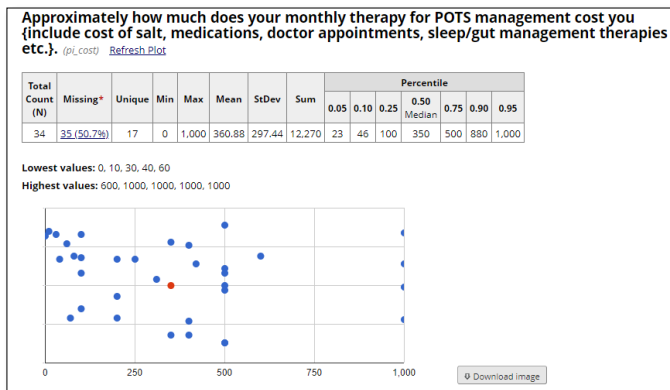


• The Foundation receives frequent complaints of lack of access to autonomic testing. This is compounded by the limited access to skilled autonomic clinicians and a lack of public funding for these assessments.

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ADARC and Australian POTS Foundation



- Assessment and treatment of dysautonomia has been precluded from medical and allied health clinical education resulting in a dearth of experienced clinicians in Australia. An average of **4.8** doctors were seen (highest = 15) before POTS was diagnosed.



- The two most common medications prescribed [Ivabradine and Midodrine] for POTS are not available on the PBS for this condition. In addition to salt and oral rehydration therapy, these medications incur a high financial burden to those patients who frequently lose income due to their illness. Average spend **\$361/month**.

### 3. The patient experience of seeking help for PASC

Despite the evidence for autonomic dysfunction in PASC and the presence of evidence-based interventions for POTS, patients are repeatedly told by clinicians that 'there is no treatment for POTS'. The following comments were collated by The Australian POTS Foundation and are included with the permission of the individuals who detailed their experiences with seeking a diagnosis of POTS after COVID infection.

- *"No Dr mentioned autonomic dysfunction to me despite me clearly articulating my symptoms were obviously occurring when standing and particularly worsening when showering. I then did my own research, focussing on UK and US reliable sources and discovered that POTS was accurately describing my symptoms and was common following COVID. I then had to research appropriate specialists using online groups and then firmly request a referral. I also looked into a POTS Long COVID research study but due to being regional and difficulty sitting up for long periods I could not travel to participate in the study".*
- *"The one Doctor apart from my GP who advocated for me in hospital in ED was from the UK and he was experienced with POTS and dysautonomia having not long come from working over there and seeing so many cases before it hits here in*

*Australia. He tried so hard to help me but was shut down but superior staff, this was so disappointing when he was literally the only one around who had any experience with what I was going through, and I was the first person in the region to present with something like I had. The specialists didn't know what to do with me, you would think they should take note of anyone with any experience even if they are of a lower rank."*

- *"After multiple months and specialist visits primarily for the persistent headache, my parents found medical literature on the links between LC and POTS. Eventually the paediatrician (my third this year) agreed that my symptoms were consistent with dysautonomia. Even so they wouldn't order specific tilt table testing for POTS but accepted that my tachycardia on standing ~40bpm increase is similar to POTS. **It's been incredibly difficult to get the medics to take LC seriously beyond treating some of my symptoms without any real desire to determine their cause**".*
- *"I am a Nurse myself and specifically brought up that I believed I had POTS after covid infection. **I was treated like a hypochondriac and told I had anxiety**, which was absolutely ludicrous as I had physical symptoms which could be simply assessed with proper awareness of postural orthostatic tachycardia syndrome. **I had many presentations to ED with no help or diagnosis whatsoever**".*
- *"Very hard to get help. I visited 3 GPs, 2 cardiologists. I ended up in ED 2 times and was admitted to hospital for 5 days due to my symptoms. None of these visits provided a diagnosis or help. On my own, I found a General Physician with experience in dysautonomia and **after months of endless tests and deteriorating symptoms, I was finally able to get a diagnosis**".*
- *"My GP dismissed this [POTS] as some newfangled thing".*
- *"GP, cardiologist and long COVID clinic all failed to sufficiently explore, test for, nor treat POTS - **the diagnosis and management advice I received only came from the Long COVID study conducted by University of Adelaide**".*
- *"When I was taken to the [a hospital] in Adelaide with a heart rate of 190 and tachycardia, **I was discharged with no answers other than long covid**. It was my ambulance officer that told me and them that I had all the symptoms of POTS. He put the name and number of [Adelaide specialist] in my phone. If it was not for him, I believe my journey would have been much longer to get answers. I was also accepted into a study. I believe I'm one of the lucky ones".*
- *[Hospital named] is one of the best and reputable hospitals in the NSW. However, they had no idea. There has to be more **training so that there is more awareness of dysautonomia** with or without previous exposure to COVID-19 infection. Simple active standing test can be performed by RN or junior ED doctor and it takes only 10 mins. My signs and symptoms demonstrated the condition that I was suffering when I first presented [to hospital]. **They .. were not listening... I am fortunate to have both financial and medical knowledge resources being a healthcare worker***

*to advocate necessary medical help for myself but not everyone is fortunate like myself.*

- *"GP agreed POTS was likely and referred to Cardiologist. **Took almost three months and calling every relevant cardiologist we could find to get an appointment and a Tilt table test.** Tilt table test staff had never assessed anybody with Long Covid before and almost messed up the test by having me sit up for the 10 minutes before the test, so HR was already elevated from my posture. HR still climbed (just) enough to diagnose POTS".*
- *"I believe I have POTS, but have no way of getting a diagnosis as **my GP does not believe me or understand what it is.**"*
- *"I had to present myself at [Hospital name] hospital by ambulance twice but I was dismissed by multiple RNs, junior and senior ED staff and the neurology team and was told from the start to finish **that I had anxiety/ panic attacks and a functional neurological disorder.** I was even asked whether I suffered from domestic violence and ever wanted to commit a suicide by mental health care team. I had to seek for further medical help and advocate my health privately thereafter."*
- *I had several Dr's in the emergency ward send me home each time after I presented with various POTS symptoms. **Not one suggestion was made that it could be POTS.** My GP had an idea and then referred me to [The University of Adelaide] study.*
- *The [Hospital named] Long COVID clinic .. and provided unhelpful advice which was contradictory to international evidence regarding Long COVID management. **They appeared to have no understanding of POTS and how to diagnose or treat this.** Thankfully I was able to self-identify that I may have POTS and seek out a specialist appointment, **and with treatment I have made considerable improvement.** With appropriate medication I have now been able to return to work part time, undertake physical exercise and do other usual daily activities.*
- *"I continue to be shocked by how few Dr's understand POTS and Long COVID, or have very ill informed understanding of these conditions. Many medical staff in Australia still seem to view COVID as a respiratory condition and don't appear to have an adequate understanding of the vascular or multi system symptoms so many of us are dealing with. I believe there are two areas that have been raised by those experiencing Long COVID and have been dismissed as 'anecdotal' despite the massive numbers, 1 is the **similarity with POTS/autonomic dysfunction (and response to treatment)** and 2 is the marked improvement for many when taking H1 and H2 blockers (particularly first-generation antihistamines combined with a H2 blocker). There also seems to be a common misconception in the medical field that autonomic dysfunction is either resulting from emotional and not physical causes or that it is a result of de-conditioning and being inactive."*
- *"The only positive arising from the large numbers experiencing Long COVID is that **hopefully advances will be made to ensure more respectful and appropriate responses for those with post viral complications in the future.** I also feel the*

*government needs to ensure supports are in place to respond to the broader impacts such as employment issues, financial impacts etc. I had a very challenging experience and was removed from my job due to being too unwell to work, unfortunately there was very little places like Fair Work or Job Watch could do to assist."*

- *"Every time I went to hospital with heart palpitations and chest pain, short breath, aches and pains they sent me home to rest."*
- ***"Patients must be listened to, no one knows their body better than themselves . This notion of brushing autonomic nervous system disorders off as anxiety etc has to stop. You cannot just be anxious standing and have a normal heart rate when sitting. POTS needs to be a nationally recognised chronic illness just like multiple sclerosis. POTS also needs an international classification of diseases code in Australia so that every patient has access to the medications that they need. Those from a lower socio-economic household, simply will not be able to access the medications that they require to function. It is embarrassing that in 2022, we are begging for an ICD code, and for POTS medications to be on the PBS system, just like other medications for other chronic illnesses."***
- *" I ended up in the Emergency Department twice and was admitted to hospital for 5 days. I had multiple tests, but none of the tests led to a diagnosis or help. **My extreme fluctuations on racing heart rate upon postural changes were either dismissed as psychogenic or I was I told that my symptoms would resolve on their own.** After months of deteriorating symptoms and after getting guidance from doctors overseas, I found a General Physician with experience in dysautonomic disorders. After a standing 10minute test, I was immediately diagnosed with Orthostatic Hypotension post-Covid and I was given treatment which has allowed me to be semi-functional. I'm still not back to normal, but I went from being 100% bedridden to being functional and independent at home."*
- *"I felt very let down, not heard and fobbed off. **GPs did not know anything about Long Covid, Dysautonomia or POTS and I was left floundering.** I joined a Face Book group "Australia Long Covid Community" it was here that I learned of a "study". I applied and was accepted. From there I have been cared for by a fabulous Cardiology team. Eventually I was put on a Chronic Disease Care Plan and a Mental Health Care Plan, but I have done the research for the Allied Health Care that I needed. I feel that GPs haven't been particularly helpful or interested and I have found it really difficult to even get an appointment."*
- *"**Long COVID clinics are presently ill-equipped to diagnose POTS, focusing heavily on respiratory symptoms only, and failing to provide relevant testing or advice when cardiac or POTS-related symptoms were raised.**"*
- *"Many Drs (including at major hospital) **unaware of post viral issues & POTS/Dysautonomia.** Told I had anxiety & that exercise would reduce symptoms. Bad advice as worsens post viral fatigue & causes increased symptom load."*

- *"Need more training for GPs Need more Cardiologists. Need more Tilt Table facilities. Tilt table testers need better training. **Ivabradine made a significant difference to my Heart Rate symptoms**, so it was startling to have the Professor (Rehab Physician, NOT Cardiologist) at the [Hospital name] Long Covid Clinic tell me he didn't believe Ivabradine worked."*
- *"Australian response has been too slow to long covid. **There is not enough support for people with long covid and POTS**. There should be ready access to tailored patient centred care, grounded in relevant clinical expertise as well as the latest research and experience from overseas (why are we not learning from the UK, US etc? They have good guidelines and considerable experience); primary care practitioners should be getting training. There should be more detailed information for patients on long covid on how to look after oneself and where to get support. There should be funding for research into causes and treatments. There should be funding for patient advocacy. There should be surveillance - meaningful measurement of the problem. **All activity I've referred to should be informed by patient lived experience.**"*

#### 4. Best practice responses regarding the diagnosis and treatment of POTS after COVID-19 infection

Assessment of Autonomic dysfunction in PASC:

- The diagnosis of POTS is based upon symptomatology and heart rate and blood pressure variations observed with postural change. The heart rate and blood pressure response to postural change can be assessed via a standing test which can be easily undertaken in the primary care setting.
- The subject must lie down for 5 minutes prior to standing still for 10 minutes. Criteria for a positive standing test is met with a sustained heart rate rise of  $\geq 30$  beats per minute in adults and  $\geq 40$  beats per minute in individuals aged 12-19 years of age (sustained for  $>30$  seconds) with the absence of orthostatic hypotension (drop in systolic blood pressure of  $>20$ mmHg within the first three minutes of standing).<sup>26</sup> An absolute heart rate of  $\geq 120$  beats per minute is also diagnostic.<sup>27</sup>
- It should be noted that the heart rate criteria has been disputed, particularly in adolescents, when a high clinical suspicion exists.<sup>28</sup>
- For those unable to manage this, a tilt table test may be required. Circadian variations in heart rate responses to orthostatic stress have been observed in this population and therefore testing is better performed in the morning.<sup>29</sup>
- Additional questionnaires such as COMPASS-31, Gastroparesis Cardinal Symptom Index (GCSI) and Fatigue Severity Score are helpful to quantitate other symptoms of autonomic dysfunction.

#### Treatment for POTS in PASC:

- Initial recommendations should focus on lifestyle modification to improve and support blood volume including fluid loading (2-3L per day), high salt diet (2 extra teaspoons per day), use of compression wear, a graded recumbent exercise program, preferably under the guidance of an exercise physiologist familiar with autonomic dysfunction, and avoidance of triggers.
- Several pharmacological options exist to support ongoing symptoms refractory to lifestyle management alone, although the evidence base is limited.<sup>30</sup>
  - Ivabradine is a select Funny channel inhibitor that assists with controlling tachycardia with no effect on blood pressure.<sup>31, 32</sup>
  - Propranolol is a non-selective beta blocker, that can be used to reduce heart rate but comes with the negative effect of lowering blood pressure in this patient population.<sup>33</sup>
  - Fluid and volume retention can be assisted with the addition of fludrocortisone which has also demonstrated improved gastrointestinal symptoms in a small case series.<sup>34</sup>
  - Midodrine is an effective alpha-adrenergic agonist that can be helpful in supporting upright posture through vasoconstriction and is generally well tolerated.<sup>35</sup>
- Whilst referral to an autonomic specialist is not required for those with mild symptoms who respond well to lifestyle changes, the majority will need some form of specialist input to manage this complex and often fluctuating condition in addition to its common comorbidities.
- Our repeated experience is that when educated about their condition, patients are empowered to implement lifestyle adjustments that reduce health seeking and unnecessary diagnostic and Emergency department presentation. Likewise, appropriate and early pharmacological intervention can reduce de-conditioning, improve orthostatic intolerance allowing the patient to actively engage in rehabilitation. There should be an active education campaign to dissuade the misguided belief that POTS is a psychosomatic disorder or that the syndrome is likely to be 'grown out of.' This trivializes the evidence that POTS is a debilitating and life altering condition that can result in profound disability, loss of earnings and social exclusion.

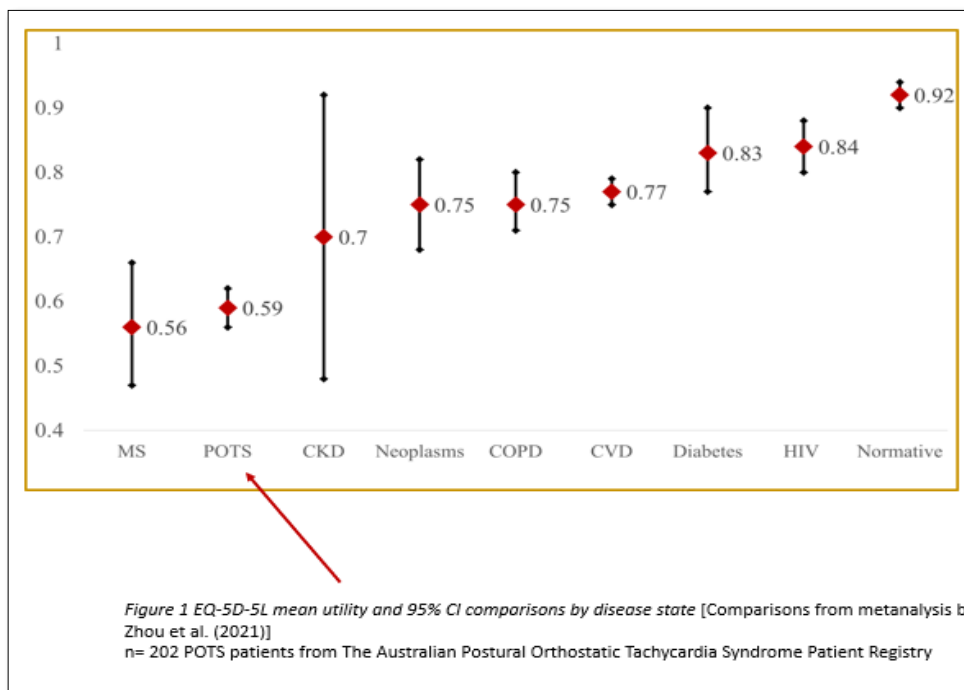
#### **4. The health, social, educational, and economic impacts in Australia on individuals who develop long-COVID**

##### Health-related quality of life in POTS

- Our study has demonstrated that those with PASC experience strikingly similar health disutility and reduced quality of life to those with POTS. This is not surprising given the striking similarity between the disorders.

- Health-related quality of life for those with autonomic dysfunction is severely impeded. ***Our clinic's experience is that approximately 25% of patients are so disabled that they are unable to attend school or work.*** This is particularly alarming given the young age and female predominance of this cohort.
- There is no discernible difference between the reduced quality of life in our patients with POTS after COVID-19 compared to POTS after other environmental causes. [As per the above study]. Below is a graph from a publication which is currently under peer review. It demonstrates the poor health-related quality of life in those with POTS compared to other major disease states and an age and gender matched normative population. ***This graph illustrates that health related quality of life in this population is poorer than that of other chronic conditions, such as cardiovascular disease and diabetes, and is akin to those living with the debilitating condition Multiple Sclerosis.***

Figure: EQ-5D-5L Health-related quality of life Utility Score [Scale 0-1; where '1' =full health].



[Seeley, M. C. et.al. (2023). Poor health-related quality of life in postural orthostatic tachycardia syndrome in comparison with a sex- and age-matched normative population. *Clin Auton Res*, 33(4), 469-477: MS-Multiple Sclerosis; CKD-Chronic Kidney Disease; COPD-Chronic obstructive pulmonary disease; CVD-Cardiovascular Disease; HIV-Human Immunodeficiency Virus]

**Our recommendations:**

- Post viral syndromes are not new and the presentation of PASC is similar to a multitude of previously reported conditions experienced after epidemic exposure. PASC is indistinguishable from similar already named and defined conditions such as POTS and ME/CFS. Recognition and treatment of these complex neuroimmune axis disorders should not be constrained by nomenclature that attaches viral causation to the syndrome definition. Such a restricted definition would preclude treatment for those who experience almost the identical condition from alternative viral, bacterial, vaccine and other environmental causes. Recommendations arising from this hearing should propose improvement in care that benefits those suffering from PASC and the thousands of other individuals who have been injured by other environmental factors and who have likewise been denied appropriate access to assessment and treatment through the Australian public health system.
- The multisystemic nature of autonomic dysfunction demands true multi-disciplinary clinical care. Our experience is that patients require multidisciplinary input from almost all allied health and medical domains. In our model, this care is best supervised by specialist nurses who can monitor compliance and titration of medication within pre-prescribed standing orders. This is similar to the model of care for the complex heart failure or diabetic patient.
- We call for urgent upskilling of medical and allied health clinicians in the assessment and management of autonomic dysfunction. This needs to have a dual approach of including education on POTS in the medical and allied health curriculums, as well as providing funding for education programs to be developed and made available for primary care and specialty physicians.
- It is imperative that technologies such as Tilt Table Testing with beat-to-beat haemodynamic monitoring and Quantitative Sudomotor Axon Reflex Testing [QSART] be adequately funded for major public hospitals and that appropriate training be given that reflects international standards for identifying and classifying autonomic disorders.
- The United States of America, Centre for Disease Control has recognised the urgent need for an ICD Code for POTS due to the rising crisis of autonomic disorders post COVID infection. In response they have implemented an emergency code in the International Classification of diseases codebook Edition 10 for POTS. We would call for an immediate consideration for a similar emergency code in Australia to allow for tracking of the impact of POTS induced by all environmental triggers including COVID-19. Hospitals should be incentivised to provide appropriate treatment and management of this condition.

## Conclusion

We are pleased to have the opportunity to present to the Inquiry the urgent need to respond to the rising crisis of **autonomic dysfunction that is caused by SARS-CoV-2**. We warn that, if not afforded due attention, this complex disorder will result in protracted and severe disability to hundreds of thousands of Australians. We reiterate that Long-COVID is not a new phenomenon. It is a new version of an old and well documented disorder. Previous generations were blinded by gender biases that attributed symptomology to 'epidemic hysteria' due to female predominance. This prevented due attendance to thorough investigation and thwarted progress and appropriate allocation of resources to research, clinical care, and treatment. It is for this reason, that we now find ourselves unable to give answers to the millions of people around the world affected by Long-COVID. We urge the Inquiry to ensure that history is not repeated in Australia, and to avoid the prejudices that have previously resulted in the medical abandonment of those with similar disorders. We look forward to the findings of the Inquiry with anticipation.

## Appendix

Written by Marie-Claire Seeley and later altered for publication in *The Conversation* [Australia]

In November 2020 data, which was later published in [The Lancet](#), was presented to the Chinese Academy of Medical Sciences. It warned of another burgeoning health crisis relating to persistent symptoms after COVID-19 including fatigue, cognitive dysfunction, palpitations, chest pain, depression, insomnia, and headache. The colloquial term 'Long COVID' was soon coined and varying iterations of the name followed with many clinicians choosing to use the more scientific descriptor, 'Post-Acute Sequelae of COVID-19' (PASC). So where do we stand now in understanding the impacts, prevalence, and prognosis for those affected by PASC?

Contrary to the public narrative, PASC is not a novel phenomenon. Varying evolutions of similarly enigmatic post infection illnesses have been documented in medical literature for decades. Striking resemblances between such conditions exist: an individual is knowingly (or unknowingly) exposed to a pathogen, acute illness of varying degrees of severity ensues and partial or complete recovery occurs. Following 'recovery' a broad range of symptoms that lead to functional decline then emerge. Two of these conditions, postural orthostatic tachycardia syndrome ([POTS](#)) and myalgic encephalomyelitis/chronic fatigue syndrome ([ME/CFS](#)) appear closely related to each other, with symptoms bearing a startling resemblance to PASC. Each have a high female predominance and frequent presence of autoimmune comorbidities. This has led to the theory that these illnesses result from a hypervigilant immune system which inadvertently causes collateral damage to the fragile autonomic nervous system while attempting to rid the body of the invading pathogen. However, there are a plethora of other theories, each equally as enigmatic as the other.

Lack of understanding of aetiology, prevalence and treatment of these syndromes is largely reflective of the broad psychosomatic stigmas attached to them. The origin of these stigmas can be traced to a series of publications in the latter half on the 20<sup>th</sup> century that addressed several outbreaks of PASC-like illnesses after exposure to unknown pathogens. In 1970, the *British Medical Journal* published an [article](#) authored by two psychiatrists who had reviewed the case notes of 198 patients from the Royal Free hospital in North London, where an outbreak of an unknown pathogen had occurred 15 years prior. The authors determined the disease had no identifiable organic origin and was therefore likely to be caused by "epidemic hysteria". Foremost amongst their justification was a disproportionate representation of women amongst those infected with the illness.

Publication of this theory in one of the most preeminent scientific medical journals of its time, gave credence to what became an enduring narrative of the psychosomatic nature of post infectious syndromes. The sequelae of this narrative has been a chronic lack of interest and investment in these debilitating 'invisible illnesses' which often render individuals unable to

work or participate in society. The burden of these systemic failings now weighs heavy on a society faced with a world-wide tsunami of post COVID conditions and goes some way to explaining the collective shrugging of shoulders by health authorities when it comes to providing answers for sufferers of PASC.

Estimates of how many people infected with COVID-19 go on to develop PASC vary anywhere from 10-40%. The large variance is a result of the initial absence of a unifying diagnostic criterion. Recently the World Health Organization has provided a [consensus definition](#) of post COVID-19 conditions which is reflective of other similar syndromes. It includes those with a history of probable or confirmed SARS-CoV-2 infection who continue to experience lingering symptoms for longer than 2 months, that are unexplained by an alternative diagnosis.

Defining the illness has allowed clearer characterisation of who is affected by PASC. PASC is now known to affect any age group and appears unrelated to initial infection severity. This evidence prompted the American Centre for Disease Control and Prevention to detail this [ominous warning](#).

Multiple [case series](#) and observational studies have now identified a high burden of autonomic nervous system dysfunction present in PASC patients. Several studies including one published in the esteemed [Journal of the American College of Cardiology](#) demonstrated that up to 95% of PASC patients meet the international criteria for POTS.

In March 2021, the American Autonomic Society released a [statement](#) warning of the rising presentations of patients to autonomic specialist referral centres with symptoms of post COVID-19 POTS. Of particular concern was the insufficient number of physicians familiar with autonomic dysfunction available to treat the condition. This situation is mirrored in Australia where there are only a handful of specialists who are familiar with managing the complex presentation of autonomic dysfunction. There are no government funded clinics in Australia and private waiting lists are now extensive.

Contrary to popular medical opinion and widely held beliefs that no effective therapies exist for PASC, there are clear [diagnostic criterion](#) and evidence-based treatments available to treat autonomic dysfunction. Early intervention is key to improving outcomes. Treatment needs to be fully explored and implemented before disability support services can be sought.

From the outset, PASC sufferers faced the same prejudice experienced by POTS/ME/CFS patients who have sought assistance through Centrelink and The National Disability Insurance Schemes. Disability insurance schemes worldwide are driven by quantifiable matrixes that allow medically unskilled workforces to assess and approve candidates for support services. These matrixes utilise stringent definitions of disability, which those with invisible illness rarely meet.

If Australia is to begin to manage the tidal wave of impairment and disability that is bearing down on its society then policy makers must heed the warnings that have been sounding for the last two years. Our health systems need to absolve themselves of the sins of the past and

pay attention to the overwhelming voice of the current sufferers of PASC and those with other post infection syndromes or invisible illnesses who have endured decades of medical neglect. Treatment options need to be made available for those with autonomic dysfunction and multidisciplinary teams need to upskill to manage these conditions. A redefining of what it is to be disabled needs to be explored and most importantly, these definitions should not be tied to a single causative pathogen but to the manifestation of symptoms that culminate in the disability.

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