Call For Change

Submission to the Australian Parliament and the Disability Royal Commission into Violence, Neglect, Abuse and Exploitation on behalf of the local and international ME and CFS community.

ME Advocates Ireland

http://meadvocatesireland.blogspot.com/

ME Australia
https://meaustralia.net/

National Centre for Neuroimmunology and Emerging Diseases - NCNED

www.griffith.edu.au/menzies-health-institute-queensland/our-institute/Infectious-Diseases-and-Immunology/neuroimmunology-and-emerging-diseases

Doctors with ME
https://doctorswith.me/

Dr. K.N. Hng

MBChB, MRCP, PG Cert in WBME, FHEA
ST7 General Internal Medicine and Gastroenterology (Ret)
Founder, Doctors with M.E.
Author of "Doctor with M.E.: My journey with 'Chronic Fatigue Syndrome' "

Dr Frank Cahill BA, Grad Dip Applied Psych, Dpsych, MAPS

Sleep Psychologist

Dr Frank Cahill is a registered, clinical and counselling psychologist who specialises in insomnia. He is a member of the Australian Psychological Society, the colleges of clinical and counselling psychologists and the Australian Sleep Association. Frank has had over 17 years of experience helping people overcome insomnia, parasomnias, anxiety, panic disorders, depression, phobias, PTSD, OCD and relationship issues.

Professor Sonya Marshall-Gradisnik BSc (Hons), PhD has been working in the field of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome with particular focus on Natural Killer Cell function and signalling pathways, T regulatory and B cell phenotypes, cytokine production, transcriptional profiling and gene expression. together with Professor Donald R. Staines she is the co-director of the National Centre for Neuroimmunology and Emerging Diseases (NCNED) at Australia's Griffith University in Queensland,
Professor Marshall-Gradisnik is also an author of the International Consensus Criteria (ICC) for ME.

Professor Donald R. Staines, MBBS, MPH, FAFPHM, FAFOEM, is a Clinical Professor at Menzies Health Institute Queensland and the co-director of the National Centre for Neuroimmunology and Emerging Diseases (NCNED) at Griffith University in Queensland, together with Professor Sonya Marshall-Gradisnik he has helped publish more than 70 peer-reviewed papers on ME and Chronic Fatigue Syndrome. Professor Staines is also an author of the International Consensus Criteria (ICC) for ME.

Eliza Charley is an actor, writer and producer with an alter-ego career as a business strategist. Her career spans work including popular TV shows: Neighbours, Secret City, Buying Blind, and Deadline Design. She also appears in the feature films: Time Apart (Amazon Prime, 2020), and The Fort (2021). In 2009, she fell ill to a dangerous virus from which her body never recovered, and as a result she now journeys with Myalgic Encephalomyelitis.

Background Context

We use the terms **violence, neglect, abuse and exploitation** because these are the key terms set out by the disability royal commission for their lines of enquiry found here: https://disability.royalcommission.gov.au/about.../key-terms

"Violence" as defined by the royal commission covers a list of behaviours and actions that include:

- Assault,
- Sexual Assault,
- Constraints, (Physical and Mental)
- Restrictive Practices (Physical / Chemical)
- Violations of Privacy & Dignity
- Humiliation and Harassment
- Financial and economic abuse (i.e. this can include denial of benefits/supports based on diagnosis discrimination, programs/clinics promoting cures or recovery for ongoing payments or scams that ignore informed consent and withhold full treatment information behind a paywall or pay as you go system) and;
- Forced Treatments or Forced Interventions

This is especially relevant to our community i.e. with the forced mandatory requirements of the Australian government to have ME patients engage in harmful and abusive therapies like GET/CBT that make them further disabled just to access services such as DSP and NDIS etc.

Stop CBT and GET immediately

We would like Australia to follow suit with the US/UK/Europe and remove GET and CBT as a cure for the disability ME and CFS. To remove harmful therapies and fund more biomedical research. We hope for more appropriate funding research, and broader funding for advocacy bodies. The old research has been formally discredited by the Cochrane Institute, as shown in this paper: Cognitive behaviour therapy for chronic fatigue syndrome

The most urgent outcome, which *must* be achieved without any further delay, has to be to *stop harming patients.*

Harm comes our way in many forms, but the most grievous of these is the Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) promoted by the PACE trial shown here: Manual for Therapists - COGNITIVE BEHAVIOUR THERAPY for CFS/ME. These therapies simply *cannot* be left in place any longer while we await the National Health Medical Research Council (NHMRC) to come up with alternative guidelines.

CBT for ME and CFS is *not* the supportive therapy that helps one cope with the psychological consequences of illness and loss. It is a form of *psychological abuse*, based on the assumption that the illness is caused by “incorrect illness beliefs” and deconditioning from lack of activity. It tries to persuade patients that they are not actually ill but are merely imagining their symptoms, and that they have an incorrect fear of activity. Seriously ill and severely debilitated patients suffering from a multi system neuro-immune disease are in essence told they will get better if they will just adopt the right thinking. In other words the patients themselves are blamed for not getting better.

This form of CBT, along with GET which patients are subjected to, directs patients to ignore their instincts and push through their symptoms to increase their activity levels. This is dangerous given the defining ME feature of Post Exertional Malaise, that is the inability to sustain more than a very low level of activity and a prolonged worsening of all symptoms if any activity over the patient’s safe level is attempted. The harder they push, the greater will be the payback, both short term and long term. Damaging CBT and GET has caused many patients to be made much worse, in many cases permanently.

Therefore, both CBT and GET need to be immediately discontinued, removed from clinical practice. These publications evidence the harm of this approach.

- Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys
- ME/CFS Illness Management Survey Results - "No decisions about me without me"
- Post-Exertional Malaise (PEM) and Graded Exercise Therapy (GET) in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Opposition to Graded Exercise Therapy (GET) for ME/CFS
- Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
- The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK (pg. 22-23)
- Summary from Invest in ME Research 9th February 2018

[Addendum: Critical review on Graded Exercise Therapy, published 2018. This shows extremely high rates of harm of between 69% to 82%.

Critical review on Cognitive Behavioural Therapy, published 2019. This shows that CBT harms one in five patients.]

In a UK petition calling for the immediate cessation of CBT and GET for ME and CFS patients has gathered over *10,822 signatures* global signatures (including Australia). Unfortunately, despite this and other efforts from the patient community, the Royal Australian College of General Practitioners (RACGP) Royal Australasian College of Practitioners (RACP), Australian Medical Association, Exercise and Sport Science Australia (ESSA) Medical Journal of Australia (MJA), The Royal Australian and New Zealand College of Psychiatrists and the NHMRC continue to follow current outdated guidelines and ignore new biomedical research, and therefore do not seem to realise or want to acknowledge the harm that is occurring for ME and CFS patients because of this. and not following the first medical training principle of "first do no harm".

In terms of future ME guidelines, CBT *must not* be recommended. *In the context of the great harm that has been done to the understanding of ME by the biopsychosocial model (BPS) of illness, CBT needs to be removed from ME guidelines altogether, for the avoidance of any* *doubt as to the nature of ME.* Ordinary supportive talking therapy can be helpful to ME patients trying to cope with suffering and loss, and some specialist ME and CFS clinics in the UK do provide such psychological support along with expert guidance on pacing techniques – that is, the correct management of activity levels in ME. However, we differ to the UK as in Australia we currently have no official specialist clinic recognised by Medicare, psychological support is not a treatment for ME and should not be viewed as such. Such a service should not be called CBT. CBT must not feature in any future guidelines for ME.

A full public enquiry on how ME has been and is being handled in Australia

This should include enquiry into:

1. **The PACE trial, The Dubbo Study, The psychiatric status of patients with chronic fatigue syndrome study** and the conduct of its authors, and the involvement of government departments and insurance industries.
    - MAGICAL MEDICINE: HOW TO MAKE A DISEASE DISAPPEAR
    - "In the Expectation of Recovery" - MISLEADING MEDICAL RESEARCH AND WELFARE REFORM
    - OFF THE PACE: CMIs, BPS, PACE, GUIDELINES and CONSEQUENCES
    - The incalculable contribution to medical science of Regius Professor Sir Simon Wessely: a thirty year retrospective.
    - Clinical Guidance for ME: “Evidence-Based” Guidance Gone Awry
    - Trial by Error: Retired PACE Investigator Peter White and Swiss Re
    - Stop The Abuse - Dr. Myhill On PACE Exposed
    - Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study
    - The Decline and Fall of an ME/CFS Researcher? the Case of Andrew Lloyd
    - Alem Matthees: how an Australian’s FOI request busted open a UK science scandal (Alem Matthees is an Australian ME and CFS advocate and PACE trial critic with severe ME. In 2016, he won a legal complaint against the institution that sponsored the PACE trial, study resulting in the first release of anonymized data by the PACE researchers)

2. **The misrepresentation of science** through the influence of the PACE authors and proponents of the biopsychosocial (BPS) model of illness in scientific publications, improperly conducted research, biased peer review including Cochrane reviews, national and international guidelines, and the role of scientific journals and their editors.

    [See above references in addition]

    - Thirty Years of Disdain - Background How HHS and a Group of Psychiatrists Buried ME

- Ending the stalemate over CFS/ME
- Special issue on the PACE Trial
- Trial By Error, Continued: The Dutch Studies (Again!), and an Esther Crawley Bonus
- Trial By Error: My Letter to Parliament’s Science and Technology Committee
- Trial By Error, Continued: Did the PACE Trial Really Prove that Graded Exercise Is Safe?
- Once Again, Lancet Stumbles on PACE
- Trial By Error: The NICE “Topic Expert” Reports
- Trial By Error: My Exchange With Archives of Disease in Childhood
- Trial By Error: Our Exchange of Views with BMJ Open
- Trial By Error: Our Latest Tango with BMJ Open…
- Trial By Error: QMUL and FOI; Nature and Cochrane; the Pineapple Fund
- Trial By Error: The Cochrane Controversy
- Comparison of SSD, BDD, BDS, BSS in classification systems
- Forward ME Group – Bodily Stress Syndrome
- ‘Lacking in transparency, ethics, and compassion’: NICE pauses publication of ME guidelines
- Delay of British chronic fatigue syndrome guidelines is a setback for people with long Covid
- Publish the NICE ME/CFS Guideline Now
- Trail By Error: Andrew Lloyds Past Endorsement of PACE
- Trial By Error: A Post About Andrew Lloyd
- Mistakes of the past: ‘The Pathogenesis of Melancholia’ and other wasted money
- [See also ‘Medical Research’ section below]

Many clinical trials have been done, and are *still* being done, investigating psychological treatments or exercise, which contain serious and unacceptable methodological flaws. Why is such flawed research being funded, over and over again, seemingly ignoring previous inadequate outcomes? For example, here is one clinical trial that studied the partners of people with ME and CFS:

> *“In chronic fatigue syndrome (CFS) little is known about how partner-related factors influence patients' fatigue symptoms and treatment outcome. We examined partners' fatigue severity, and determined the role of partner-related factors for patients' symptoms and the outcome of cognitive behavioural therapy (CBT).”*

Are patients' partners and spouses now to be trained to extend the psychological abuse already being thrown at them by their health service, into their homes?

In Australia we had this sexist study asking if women with ME and CFS were simply "Ovary-acting" The following quote is taken directly from the trial's UNSW post: study: Impact Of Fatigue In CFS – Call For Research Participants the University of New South Wales asks the question "Are women with CFS ovary-reacting?
Is Australian research now harking back to the days of wandering wombs and hysteria? Conversely are we to assume that men with ME and CFS are simply being "testie". One must wonder how this study even passed an ethics committee.

Here the mainstream medical literature promotes a *dangerous* and *abusive* therapy for *children* with CFS and ME – such is the influence of the biopsychosocial (BPS) school. Serious ethical concerns have been raised relating to this therapy (the Lightning Process), and the publicly funded clinical trial that experimented on children with it.
Training course for chronic fatigue syndrome effective for children alongside specialist care
Dr. Crawley's failure to adequately assess risk associated with the intervention and failure to
disclose risks to SMILE study participants – patient reports of the Lightning Process
SUPPORTING EVIDENCE FOR GMC COMPLAINT AGAINST DR. ESTHER CRAWLEY 1
SUPPORTING EVIDENCE FOR GMC COMPLAINT AGAINST DR. ESTHER CRAWLEY 2
Lightning Process | Advertising Standards Authority adjudication on Phil Parker Group Ltd | 22 August 2012
[See also links in *the unethical use of children*.]

3. The misrepresentation of science through **control of the media**. The Science Media Centre has played a key role in this in the UK and this is also occurring in Australia:
The Role of the Science Media Centre and the Insurance Industry in ME/CFS: the facts behind the fiction
Trial By Error, Continued: A Few Words About "Harassment"
Trial by Error: The Science Media Centre's Desperate Efforts to Defend PACE

Forward-ME Group Letter – Science Media Group

I'm not your inspiration, thank you very much

Resisting Attempts to Silence #PwME

‘Insight’ on chronic fatigue syndrome: Andrew’s experience

Inspiration porn and the objectification of disability: Stella Young at TEDxSydney 2014

The above TED talk by Stella Young highlights the dangers of “inspiration porn” in the disability community. “Inspiration porn” leads to objectification but also exploitation of patients with ME and CFS. This is because it leads to the unhealthy public perception becoming “well look at that person and how they overcame their illness, why haven’t you?”. In the ME community, “inspiration porn” has led us to being continually dismissed, disbelieved and discriminated against.

Publicization of certain sporting stars and celebrities claiming they were ‘cured’, ‘recovered’, or live a ‘normal life now’ has gained these individuals notoriety but perpetuated real harm on the rest of the community.

'Potentially harmful and old-fashioned' chronic fatigue treatments under review

Layne Beachley shares how she fought her way back from depression, CFS and suicidal thoughts

Fitness queen reveals secret weapon helping her fight shock diagnosis

AFL legend Alastair Lynch's battle with chronic fatigue

Insight: Chronic Fatigue Syndrome

Because these “inspiration porn” stories are all we tend to hear about ME and CFS in the public, these stories end up guiding the narrative and impact government policy, medical biases, and access to social programs such the NDIS and DSP.

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4. **The unethical use of children** in dubious clinical trials of dubious and potentially harmful treatments. Something is seriously wrong with the research structure and oversight when such things are allowed to happen, and we use this research to justify unethical treatments on children in the UK and Australia.

The SMILE Trial Lightning Process for Children with CFS: Results too good to be true?

MEA Review: The SMILE trial – a lesson in how not to conduct clinical trials in people with ME/CFS | 12 October 2017

Trial By Error: The SMILE Trial's Undisclosed Outcome-Swapping

Trial By Error: No Ethical Review of Crawley School Absence Study

5. A close look at the phenomenon of so-called **Medically Unexplained Symptoms (MUS)** infiltrating our National Health Service, and the new UK Improving Access to Psychological Therapies (IAPT) programme (equivalent to the Mental Health Care Plan in Australia). Why are such diverse symptoms as paraesthesia (tingling), tremor and visual disturbance, and conditions such as Migraines, CFS, ME, Fibromyalgia and Irritable Bowel Syndrome listed as MUS on this NHS page?

Medically unexplained symptoms

These symptoms could well be signs of serious illness, and the listed conditions are absolutely NOT medically unexplained, with plenty of scientific evidence pointing to physiological explanations. No surprises on the treatments suggested either – Cognitive Behavioural Therapy, exercise, and anti-depressants!

The following *guidelines* issued by the Royal College of General Practitioners and the Royal College of Psychiatrists lists

- pain in different locations
- functional disturbance of organ systems
- complaints of fatigue or exhaustion

as likely symptoms of MUS, despite them being symptoms of many organic diseases, and all of them being common symptoms in ME, Fibromyalgia and auto immune conditions. Royal College of Psychiatrist Medically unexplained symptoms.

It also states that MUS should be considered if a patient has the following!

- physical symptoms
- for 3 months
- affecting functioning

Then it goes on to discourage doctors from investigating the patient's complaints, and to use "word scripts" in order not to let a doctor's anxiety and uncertainty take over (box on pg.3). It further points doctors to IAPT pathways.

This is relevant in Australia as Royal Australia New Zealand College of Psychiatrists

(RANZCP) and RACGP use the exact same assessment criteria
EPA2 Medically unexplained symptoms
Chronic fatigue syndrome - A patient centred approach to management
Difference between Australian chronic fatigue syndrome guidelines and ME
Have a look at what the current Australian CFS guidelines say...and what we need in future guidelines.

These guidelines are the ones used in Australia and are outdated from 2002, meaning they are over 20 years old:
Chronic fatigue syndrome
Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management
Chronic fatigue syndrome - Clinical practice guidelines — 2002

The NHMRC rules say all their guidelines are to be reviewed every five years and at 10 years they are automatically outdated. These guidelines should have been reviewed in 2007 and outdated in 2012. Yet NHMRC have ignored their own processes and have let dangerously outdated guidelines to be continued for use with no disclaimer that they are out of date for medical professionals or government departments that might be using or referring to them

This article by ME Australia highlights some of the issues of these outdated guidelines:
"*Back in the 1990s, the federal government saw a need and commissioned guidelines on diagnosis and treatment. In 2002 the Australian chronic fatigue syndrome clinical guidelines were published after being commissioned by the National Health and Medical Research Council (nine years after the process started). They were heavily criticised for having a bias towards the psychological, dismissing biological evidence and omitting severely affected patients. Within weeks of their publication, the Australian Senate called for their immediate review, noting the guidelines were both inadequate and failed to reflect the consultation process.*

Compared to the International Consensus Primer on ME for Medical Practitioners, the Australian guidelines fail to take patients concerns seriously; deny it is a 'disease'; state it is on the 'spectrum of fatigue' and that there are 'no abnormal findings'. The guidelines recommend cognitive behavioural therapy to "identify beliefs which beliefs, attitudes and *behaviours holding back recovery" and many more troubling statements."*

ME/CFS South Australia also expressed their concerns about these guidelines to the MJA back in 2002 yet were met with a less than satisfactory response. The full conversation can be viewed here

ME/CFS SA stated in 2002:

"After an in-depth analysis of the Guidelines, an evaluation of the available evidence and extensive discussion with people with CFS, the Association is firmly and unanimously of the opinion that publication will result in:

- *further cases of misdiagnosis;*
- *inappropriate and inadequate medical care; and*
- *the promotion of widespread misconceptions about the illness,*

with potentially far-reaching and long-lasting, adverse effects for the 40-140,000 Australians with CFS.

More specifically it is considered that the Guidelines:

- *do not describe accurately and fully the symptoms and characteristics of the illness;*
- *misrepresent the illness and people with CFS;*
- *do not provide an accurate, balanced and objective consideration of the research evidence;*
- *demonstrate a consistent bias towards a psychiatric-psychological approach to the illness;*
- *dismiss, downplay or ignore biological evidence;*
- *make illness management suggestions that are potentially harmful for many with CFS; and*
- *do not mention other ways of effectively managing the illness."*

MJA's response to ME/CFS SA seemed to be more concerned about protecting the guidelines authors from perceived "censorship" rather than listening and engaging with patients with lived experience and addressing or alaying legitimate concerns of patient harms raised by ME/CFS SA.

What's even more concerning is the MJA is ignoring the very basics of the scientific method which is: a method wherein inquiry regards itself as fallible and purposely tests (and retests) itself and criticizes, corrects, and improves itself especially when approached with new evidence, inquiries and objective data.

It's almost laughable that a scientific publication like the MJA would accuse ME/CFS SA of supposed "censorship" rather than focus on improving and strengthening their scientific method. One could almost assume the MJA has fallen victim to confirmation bias and running a protection racket for eminence based publications rather than evidence based research methodology.

As patients we find these guidelines *condescending and dismissive.* Of course, patients do sometimes have symptoms which stem from secondary anxiety or depression. However, *we do not see the need to have official guidelines which encourage the preconceived idea of non-pathology*, specifically telling doctors how to *not* help us. Doctors should be credited with enough intelligence to investigate as they see fit, and then decide for themselves after gathering the right evidence, whether to diagnose an organic condition or to dispense appropriate reassurance.

This review article in the Emergency Medical Journal on *Medically Unexplained Physical Symptoms (MUPS)* lists Chronic Fatigue Syndrome (CFS), Fibromyalgia and Multiple Chemical Sensitivity (MCS) as Functional Somatic Syndromes, even though they, and many other conditions on the list, are *not* medically unexplained. MCS is a common symptom of ME, and CFS is the NHS name for ME. With the BPS brigade's concerted and sustained campaign of dismissal of ME, it is no wonder doctors view ME patients as lazy malingerers or hypochondriacs!
Medically unexplained physical symptoms in emergency medicine
Ending the stalemate over CFS/ME

The UK charity Invest in ME Research (IiMER) expresses similar concerns, highlighting "buzzword-groupings" such as *Functional Neurological Disorder (FND)*, *MUS* and *IAPT* as modern-day creations being focused towards ME. This is not just a British phenomenon. Dx Revision Watch and Mary Dimmock show how CFS, ME, Fibromyalgia and Irritable Bowel Syndrome could very soon all be diagnosed as *Bodily Distress Syndrome* or *Bodily Stress Syndrome* under the upcoming International Statistical Classification of Diseases and Related Health Problems 11th Revision *(ICD-11),* and the British group Forward-ME, led by the Countess of Mar, expresses similar concerns about proposed changes to the ICD.

The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK
Comparison of SSD, BDD, BDS, BSS in classification systems
“BODILY STRESS SYNDROME” INFO SHEET

This open letter discusses *NICE’s previous role in the IAPT programme.* We agree with Dr. David Tuller that any IAPT roll-out should have been halted until the position of ME and CFS (and many other conditions) on it had been clarified.
Trial By Error: A Letter to NICE About the IAPT Program

The appointment of various individuals to high positions in government, advisory committees, insurance and other related policy and organisational groups and endeavours needs a drastic overhaul to ensure that people with ME and CFS are leading the decisions that affect them. This occurs in both Australia and the UK.

Another alarming development would be the appointment of those that align to the biopsychosocial (BPS) model of treatment for ME and CFS, and who have been heavily criticised by patients, doctors, and research peers, being given the power to govern over significant and important decisions, policy, research and organisations that relate to ME and CFS and other conditions. The same people also classify a whole host of conditions as *“Functional Somatic Syndromes”* including Irritable Bowel, Non-ulcer Dyspepsia, Non-Cardiac Chest Pain, Fibromyalgia, Tension Headache, ME and CFS, Multiple Chemical Sensitivity, Chronic Pelvic Pain and Tempero-Mandibular Joint Dysfunction.

Are we wanting to sentence ever growing numbers of patients to the same dismissal and abuse that has been thrown at ME and CFS patients? Is this the purpose of the Medically Unexplained Symptoms and the review of the Mental Health Act?? And *why* in this country, *do we diagnose children with* Pervasive Refusal Syndrome, *a condition which does not exist* either in the International Statistical Classification of Diseases and

Related Health Problems 10th Revision (ICD-10) for 2016, or the Diagnostic and Statistical Manual of Mental Disorders (DSM–5)? The listed *symptoms* of the purported Pervasive Refusal Syndrome sound *remarkably similar to symptoms of ME.*
G160(P) Case series of Pervasive Refusal Syndrome presenting with Chronic Fatigue Syndrome: avoiding the pitfall of a wrong diagnosis
False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis (ME)International Statistical Classification of Diseases and Related Health Problems (ICD)
Diagnostic And Statistical Manual Of Mental Disorders, Fifth Edition

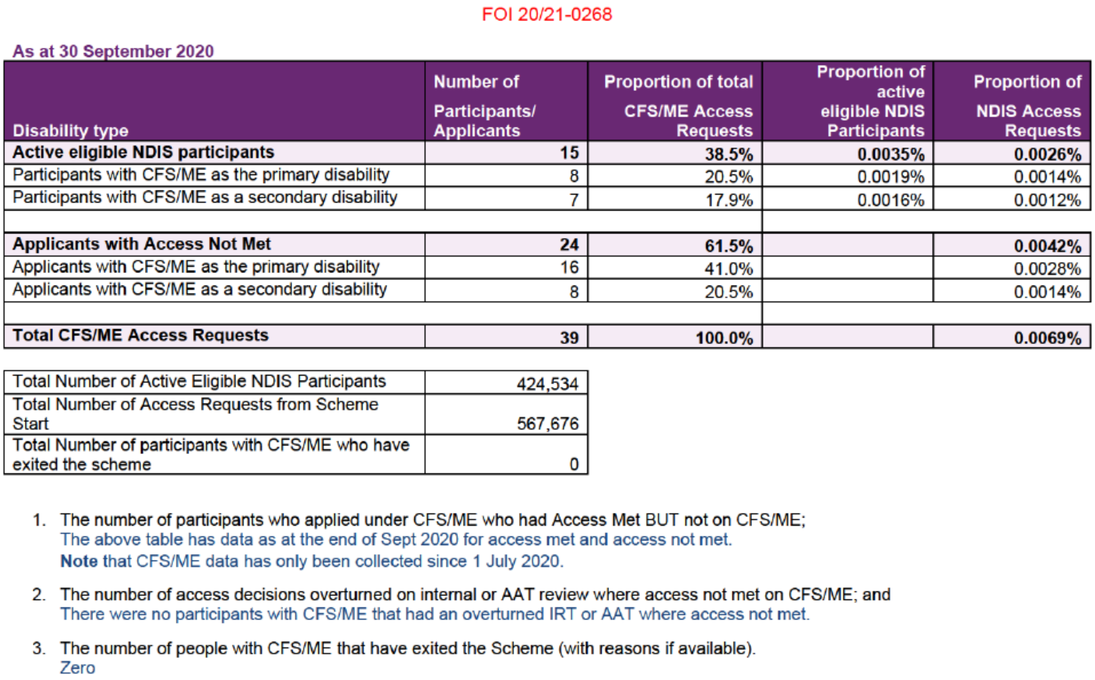
Mental Health legislation is already being (mis)used to *deny basic human rights* to seriously ill people. *With this not-so-independent review of the Mental Health Act, how much more power will BPS proponents now wield over ever-increasing categories of sick and disabled people?*
The incalculable contribution to medical science of Regius Professor Sir Simon Wessely: a thirty year retrospective.
Voices from the Shadows

There is an increasing history of the biopsychosocial model of illness and treatment, writing off legitimate physical conditions as psychosocial, and therefore increasing the abuse and neglect to those experiencing these conditions as they are dismissed.
DSM-5 Makes Way for Misdiagnosis of Physical Illness as Mental Disorders

The widespread alignment with the BPS model in governments, insurance and major health organisations leads to abuse, neglect, violence and exploitation of those with chronic health conditions and disability because it is used to deny people access to reasonable and necessary adjustments and treatments. For example, the Independent Assessments proposed for the NDIS aligns with the BPS model and denies people access to the NDIS.
Submission to the National Disability Insurance Scheme Inquiry into Independent Assessments
ME/CFS National Disability Agreement Review Submission

6. **Examination of the so-called “secret files' 'on ME and CFS**, held by the NMHRC,

RACGP, RACP, Department of Health, NDIA, and the Department of Social Services. It is believed that information and correspondence contained within these files show how certain parties have influenced how ME is perceived and treated by our social welfare system, our health service, our insurance companies, the NDIS and our research funding bodies. Parts of these files have been released through Freedom of Information requests and make interesting reading (see below). It seems the NDIA only just started recording ME and CFS data since the 1st July 2020. Emeritus Professor of Medicinal Chemistry Malcolm Hooper's "MAGICAL MEDICINE: HOW TO MAKE A DISEASE DISAPPEAR" and Brian M Hughes Psychology in Crisis is also highly revealing. https://medicalerrorinterviews.podbean.com/e/brian-hughes-psychology-in-crisis-an-interview-with-the-psychologist-and-author/



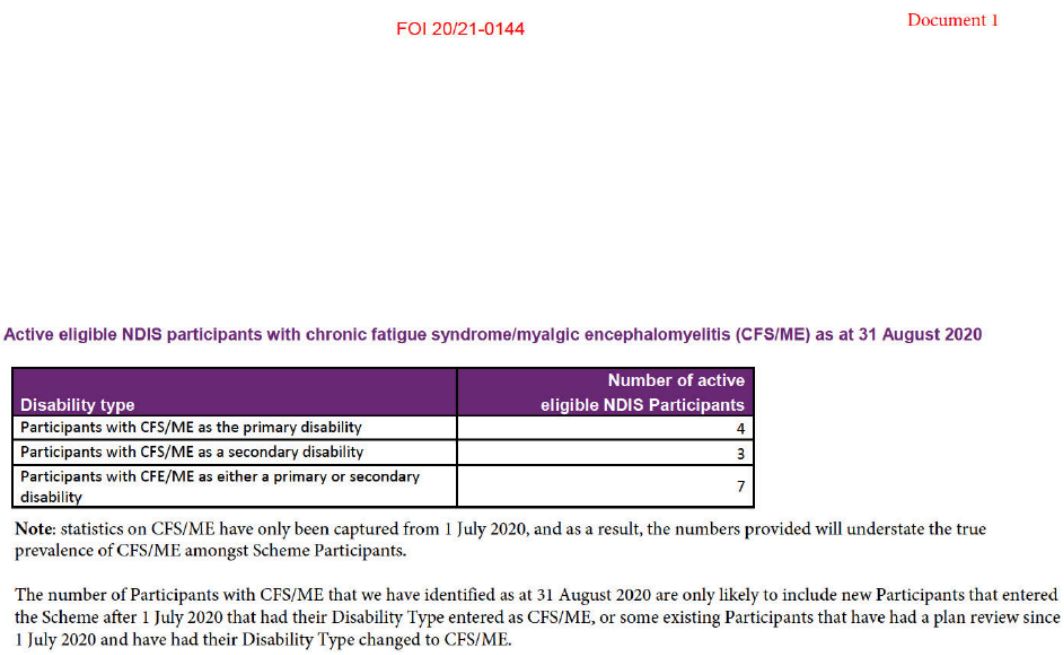
FOI 20/21-0268

As at 30 September 2020

Disability type	Number of Participants/ Applicants	Proportion of total CFS/ME Access Requests	Proportion of active eligible NDIS Participants	Proportion of NDIS Access Requests
Active eligible NDIS participants	**15**	**38.5%**	**0.0035%**	**0.0026%**
Participants with CFS/ME as the primary disability	8	20.5%	0.0019%	0.0014%
Participants with CFS/ME as a secondary disability	7	17.9%	0.0016%	0.0012%
Applicants with Access Not Met	**24**	**61.5%**		**0.0042%**
Applicants with CFS/ME as the primary disability	16	41.0%		0.0028%
Applicants with CFS/ME as a secondary disability	8	20.5%		0.0014%
Total CFS/ME Access Requests	**39**	**100.0%**		**0.0069%**

Total Number of Active Eligible NDIS Participants	424,534
Total Number of Access Requests from Scheme Start	567,676
Total Number of participants with CFS/ME who have exited the scheme	0

1. The number of participants who applied under CFS/ME who had Access Met BUT not on CFS/ME;
   The above table has data as at the end of Sept 2020 for access met and access not met.
   Note that CFS/ME data has only been collected since 1 July 2020.
2. The number of access decisions overturned on internal or AAT review where access not met on CFS/ME; and
   There were no participants with CFS/ME that had an overturned IRT or AAT where access not met.
3. The number of people with CFS/ME that have exited the Scheme (with reasons if available).
   Zero



FOI 20/21-0144

Document 1

Active eligible NDIS participants with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) as at 31 August 2020

Disability type	Number of active eligible NDIS Participants
Participants with CFS/ME as the primary disability	4
Participants with CFS/ME as a secondary disability	3
Participants with CFE/ME as either a primary or secondary disability	7

Note: statistics on CFS/ME have only been captured from 1 July 2020, and as a result, the numbers provided will understate the true prevalence of CFS/ME amongst Scheme Participants.

The number of Participants with CFS/ME that we have identified as at 31 August 2020 are only likely to include new Participants that entered the Scheme after 1 July 2020 that had their Disability Type entered as CFS/ME, or some existing Participants that have had a plan review since 1 July 2020 and have had their Disability Type changed to CFS/ME.

Major takeaways is that the NDIS is still relying on outdated data and dodgy studies.
Below is the "evidence" assessors are using to force ME patients into harmful GET/CBT treatments. Just one problem, the "evidence" from NICE they are using no longer exists, and the draft report they do quote from NICE disproves/invalidates all the "evidence" they are relying on. Their standards on what they expect ME/CFS patients to do are below:
"There is still little evidence to support any particular management or intervention for CFS in primary care that can provide an effective early intervention [33]. The only two evidence based therapies recommended by NICE are:
Cognitive Behavioural Therapy

- Five to 16 sessions. Sessions ranged from 30 minutes to 150 minutes [34]
- People with CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in CFS [32].

Exercise Therapy

- Duration of the exercise therapy regimen varied from 12 weeks to 26 weeks o three and five times per week, with a target duration of 5 to 15 minutes per session using different means of incrementation, often exercise at home [35]

31. Working Group of the Royal Australasian College of Physicians. Chronic fatigue syndrome."

Also, this is the list of evidence the NDIS are relying on, only two are from the last 5 years and one of those were dismissed by Cochrane itself for using an out of date evidence and poor research methodology.

Evidence: Clinical practice guidelines- 2002. Med J Aust [Internet]. 2002 May 6; 176(S9):[S17-s55 pp.].

- This is a paper that even the NHMRC admits is 20 years out of date, was failed to be updated by its own researchers in 2007, and based on poor or out of date evidence and rejected by the ME/CFS community at the time

Evidence: 32. National Institute for Health and Care Excellence (NICE). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. 2020. Available from: https://www.nice.org.uk/guidance/ng206/documents/draft-guideline

- They quote inflammatory statements from the 2007 NICE guideline yet are using the 2020 NICE draft guideline that completely invalidates their previous claims as evidence! Of course the 2021 NICE guidelines now supercede and replace any of the old recommendations

Evidence: 33. Hughes JL. Chronic Fatigue Syndrome and Occupational Disruption in Primary Care: Is There a Role for Occupational Therapy? British Journal of Occupational Therapy [Internet]. 2009 2009/01/01; 72(1):[2-10 pp.]. Available from: https://doi.org/10.1177/030802260907200102.

- Another study that is now 13 years out of date, NDIA used this study to validate the use of GET/CBT as doctors in the study stated "cognitive behavioural therapy and graded exercise therapy as more beneficial than medical care for CFS/ME" yet the NDIA ignored studies own results/conclusions which said "Currently, there is little research evidence to support any particular interventions for people with CFS/ME" and "57% of people with CFS/ME (in the study) reported that they had received unhelpful advice and/or treatment from their GP"

Evidence: 34. Price JR, Mitchell E, Tidy E, Hunot V. Cognitive behaviour therapy for chronic fatigue syndrome in adults. Cochrane Database of Systematic Reviews [Internet]. 2008; (3). Available from:https://doi.org//10.1002/14651858.CD001027.pub2.

- This study is now outdated and 19 years behind current research. Cochranes own comments on the study "This 2008 review predates the mandatory use of GRADE methodology to assess the strength of evidence, and the review is no longer current. It should not be used for clinical decision-making. The author team is no longer available to maintain the review." https://www.cochrane.org/.../DEPRESSN_cognitive-behaviour...

Evidence: 35. Larun L, Brurberg KG, Odgaard-Jensen J, Price JR. Exercise therapy for chronic fatigue syndrome. Cochrane Database of Systematic Reviews [Internet]. 2019; (10). Available from: https://doi.org/10.1002/14651858.CD003200.pub8

- Cochrane itself has now discredited and reviewed this study https://www.cochrane.org/news/cfs there most damning statement about this study here: "This amended review is still based on a research question and a set of methods from 2002, and reflects evidence from studies that applied definitions of ME/CFS from the 1990s. Having heard different views expressed about the evidence base for this condition, we acknowledge that the publication of this amended review will not resolve all the ongoing questions about this globally important health topic. “We have decided, therefore, that a new approach to the publication of evidence in this area is needed; and, today we are committing to the production of a full update of this Cochrane Review, beginning with a comprehensive review of the protocol, which will be developed in consultation with an independent advisory group that we intend to convene. This group will involve partners from patient-advocacy groups from different parts of the world who will help us to embed a patient-focused, contemporary perspective on the review question, methods and findings.”

The Secret Files Unwrapped: Part 2 – Control, not Collaboration (with file download)

The National Archives 1

The National Archives 2

7. The General Medical Council's role in the **persecution of doctors** who, against the grain, have genuinely tried to help their ME patients with a biomedical approach to the illness in the UK. This is also relevant to Australia with the RACGP and the NHMRC. One can only imagine that this persecution has contributed to the dearth of good doctors willing to take their ME patients seriously and stray from our *unhelpful* national guidelines.

Ignoring the Elephant in the Room

Category: My GMC Hearing

Donald Lewis

In Australia we saw the AMA appoint Doctor of the year (voted for by patients) to Dr Don Lewis who the AMA, RACGP, NHMRC persecuted Dr Lewis's biomedical approaches as "unconventional" despite his continuing contributions to research and patient care for patients with ME (I.e. ICC guidelines, GP primer etc)

GP awarded by Australian Patients Association

The above ME specialists have been given undue harassment by the GMC, NHMRC, RACGP et al, seemingly with a *"guilty until proven innocent"* approach, and there may be others. Yet these organisations is *still to make a decision on whether to investigate the PACE authors*, who were *referred* to them six months ago [Addendum: They were referred *in January 2018] for scientific fraud.* It would be interesting to know if those responsible for conducting *unethical clinical trials on children*, and who endorses the contentious *Pervasive Refusal Syndrome*, have ever been proportionately disciplined, or even investigated!

Dr. Myhill Calls For The GMC To Investigate The PACE Trial Authors

Dr. Crawley's failure to adequately assess risk associated with the intervention and failure to disclose risks to SMILE study participants – patient reports of the Lightning Process

SUPPORTING EVIDENCE FOR GMC COMPLAINT AGAINST DR. ESTHER CRAWLEY

G160(P) Case series of Pervasive Refusal Syndrome presenting with Chronic Fatigue Syndrome: avoiding the pitfall of a wrong diagnosis

[See also links in *the unethical use of children*]

[Addendum: The PACE authors were referred to the GMC for investigation in January

2018. It took the GMC six months to confirm the decision not to investigate. The GMC did not provide satisfactory evidence for that decision, even after further correspondence. It became necessary for ***the** Information Commissioner's Office, finding the GMC in breach of the Freedom of Information Act 2000,* to issue a Decision Notice on 30th September 2019, requiring the GMC to provide said evidence.]

The call for a public enquiry is unanimous. The UK charity Invest in ME Research (IiMER) describes the dismal status of research, treatment and perception of ME in the UK, and calls for a public enquiry. Dr. Sarah Myhill, ME and CFS specialist and much persecuted by the GMC, calls for a public enquiry in her Medical Abuse in ME Sufferers (MAIMES) campaign. Now we, the rest of the ME community – ME organisations, charities, patient groups, doctors, scientists, academics, patients and individuals all across the world, join the call for a full public enquiry.

The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK

Stop The Abuse - Dr. Myhill On PACE Exposed

Enquiry into the guidelines used in Australia

The guidelines Australia is currently using reflect the 2007 NICE guidelines which have recently been superseded by the 2021 NICE guidelines. The new 2021 guidelines are not currently used in Australia.

In response to Freedom of Information requests to the NDIA, we see these outcomes.

The Good:

- "The Agency accepts that the 2021 NICE Guidelines now replace the previous 2007 NICE guidelines."
- "The NDIA is moving to a new ICT system and will update to ICD-11 in this new system during 2022-2023."

The Bad:

The Agency has no intention to add any new conditions to list B of permanent conditions. Yet they contradict themselves later by saying "The use of automatic lists does not fully align with the access requirements of the act and rules"

By the time NDIA update their ICD codes (approx two years) new ICD codes will have already likely been created.

"The Agency is also aware of the statement from a number of senior medical groups in response to the 2021 NICE guidelines including:

- Royal college of physicians
- royal college of physicians Edinburgh
- royal college of general practitioners
- royal college of psychiatrists
- academy of medical royal colleges
- faculty of sport and exercise medicine
- faculty of occupational medicine

(Their disgusting response which the NDIA are referring to is here

Re: credibility of the royal colleges these articles explain why their opinion is wrong here and here

It should be noted that no individual has publicly put their name to this document that the NDIA are referring to. Therefore, it has not been endorsed. Conversely, the NICE guidelines are “commissioned by NICE and developed at the National Guideline Centre which is hosted by the Royal College of Physicians.” (see here). So it seems yet again the NDIA are cherry-picking the sources they are endorsing and using.

So why on earth are the NDIA ignoring an independent government regulator and instead choosing to still rely on what is essentially (by Australian standards) Industry lobbyists? Lobbyists that hold extreme bias, vindictive & vested interests and actively tried to undermine the integrity of NICE's independent review processes?

These are groups that presented "evidence" to NICE which NICE itself came to the conclusion was of "poor to very poor quality" the fact that the NDIA would even consider these views are extremely concerning.

- In response to the NDIA using two guidelines that are now in direct conflict with each other (the 2002 outdated Australian guidelines and the and 2021 NICE guidelines) the agencies response was:

> "NDIA response: As above, treatment guidelines are used to determine whether ‘the person’ applying for access to the Scheme has been fully treated prior to any impairment that meets the criteria listed in s24.1(a) or s25.1(b) being assessed as permanent. All treatment recommendations from any relevant guidelines are considered.
>
> The Agency has no position on the difference in the 2007 and 2021 Guidelines nor whether their recommendations are conflicting. In the absence of any further evidence-based guidance clarifying treatment recommendations for ME/CFS, they will be collectively used together with other expert opinion to assess whether any person applying for access to the Scheme with ME/CFS has explored and/or trialled all the treatment options they recommend."

Therefore, no word on who these experts are. Unfortunately, this isn't good news as the agency is still choosing to continue to use BOTH NICE guidelines from 2007 and 2021 even though the new 2021 NICE guidelines OFFICIALLY replaces the old 2007 ones. If NDIA continues to choose to use the old 2007 NICE guidelines they legally cannot have NICE's backing or endorsement, and for all intents and purposes the 2007 guidelines legally no longer exist.

No response on the outdated and expired 2002 Australian guidelines. Even though the new and current 2021 NICE guidelines discredit GET/CBT and the old outdated and expired 2002 Australian guidelines still strongly advocate for their use. These documents clearly contradict each other yet the NDIA are happy to cherry pick which "evidence" suits them better to either deny or give access to ME patients trying to enter the scheme.

The NDIA also stated: "As above, despite this reported conflict, in the absence of any further evidence-based guidance clarifying treatment recommendations, the Agency will use all available guidance, relevant to the particular individual case, to consider whether a person applying for access to the Scheme has fully explored and/or trialled all recommended interventions for ME/CFS. This is a consistent approach used for all access decisions, not just ME/CFS."

Yet, the NDIA have clearly ignored these current updated guidelines from the Mayo Clinic, the USA, CDC, the UK and Europe all Published recently that all discredits GET and CBT

US ME/CFS Clinician Coalition

Mayo Clinic

European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE)

CDC guidelines on ME/CFS

So why are the NDIA so attached to guidelines that are expired, out of date or now non existent? (i.e. the 2002 Australian guidelines and 2007 nice guidelines?) Who are they looking out for? It certainly isn't ME and CFS patients.

Again we sought to get a response on who the NDIA are getting this faulty and dangerous advice from and yet again the agency have avoided to fully answer the question

The NDIA response was: "The Agency receives approaches from several peak bodies. For ME/CFS this has been predominantly Emerge and to a lesser extent ME/CFS Australia. The Agency consistently engages with a range of Peak Bodies."
"There was no tender process involved in the above process. The Agency communicates and engages with all Peak bodies that seek to connect with us. The NDIA accesses information as needed from a range of various sources."

We do not know who these other 5 "peak bodies" or their representatives are, or if any public oversight from the ME/CFS community was made to make sure that any harmful GET/CBT advocates/practitioners or lobbyists were excluded.

But I know one thing for sure and I will bet my life that neither Emerge Australia Inc, or ME/CFS Australia were responsible for delivering this negligent advice to the NDIA. I believe the NDIA are being disingenuous by only naming these two orgs rather than the party/parties actually responsible and I'm more than 100% sure It's more than likely that a GET/CBT practitioner with a highly vested interest in keeping the status quo is the one giving them this advice.

On the ICD codes the agency's response was this: "ME/CFS has been recorded in the system since 1 July 2020. (when we made our first FOI request) The ICD-10 code is R53.8 (Chronic fatigue/ME)." which is listed under "other malaise and fatigue"
Yet Myalgic Encephalomyelitis (ME) on the ICD - 10 code is listed under G93.3 under other disorders of the nervous system. So yet again the NDIA are cherry picking the terms and data they want to use to help or deny access to patients.

Equivalent funding for biomedical research on ME

Firstly, this means putting a stop to the endless pursuit of Cognitive Behavioural Therapy, Graded Exercise Therapy or other psychological therapies in ME and CFS, when these have already been proven to be *ineffective* in ME and CFS. *Public funds need to be spent on biomedical research and not further futile attempts to prove that ME or CFS is due to "incorrect illness beliefs" and deconditioning.* Any such studies which are ongoing or in the pipeline should be cancelled and funds redirected to more useful ventures.

Examples of inappropriate research:

Completed studies and their critiques:

- Special Issue: The PACE Trial
- Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT
- Trial By Error, Continued: Why has the PACE Study's "Sister Trial" been "Disappeared" and Forgotten?
- Not So Fine After All: the FINE Trial Crashes to Earth
- 'Failure of FINE trial comes as no surprise' – MEA responds to study results in British Medical Journal
- Trial by Error, Continued: More on Graded Exercise from Peter White and The Lancet
- Patient experiences and the psychosocial benefits of group aquatic exercise to reduce symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: a pilot study
- PASS THE SNUFF AND LOOSEN THE CORSETS – THEY'RE BACK TO RESEARCHING HYSTERIA
- TYMES Trust/ME Association joint statement on Lightning Process study in children
- Pacing, Conventional Physical Activity and Active Video Games to Increase Physical Activity for Adults with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Protocol for a Pilot Randomized Controlled Trial

Current or upcoming studies:

The "shopping bag study":

To investigate the effectiveness and cost-effectiveness of using FITNET-NHS (an online CBT programme) compared to online activity management to treat paediatric

CFS/ME in the UK.
Trial By Error: The Shopping Bag Study; and New York State's Revamped Website
Investigating the effectiveness and costeffectiveness of FITNET-NHS (Fatigue In Teenagers on the interNET in the NHS) compared to Activity Management to treat paediatric chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME): protocol for a randomised controlled trial
Volunteer for research investigating Chronic Fatigue Syndrome
Trial By Error, Continued: The New FITNET Trial for Kids
Trial By Error, Continued: A Follow-Up Post on FITNET-NHS

Secondly this means equivalent funding commensurate with the illness burden (250,000 patients in the UK) and economic burden (£3.3 billion pounds per year) of ME. For comparison, Multiple Sclerosis (MS) , which affects only half as many people, receives seven times as much research funding. Not only should ME receive equivalent research funding going forward, it deserves a compensatory increase in funding in order to catch up with 30 years of gross underfunding and to move forward scientific understanding, diagnosis and treatments for ME sufferers.
The truth about NHS research funding that should shame the government
Counting The Cost - Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
ME/CFS Research Funding - AN OVERVIEW OF ACTIVITY BY MAJOR INSTUTIONAL FUNDERS INCLUDED ON THE DIMENSIONS DATABASE
The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort

In Australia ME and CFS funding was only promised 3 million dollars in 2019, much less than comparable illnesses such as MS, cancer. We are delighted to hear at the debate that the NIHR and MRC will be speaking to the UK CFS and ME Research Collaborative (CMRC) and the UK ME and CFS Biobank about making progress with biomedical research on ME. We would strongly urge them to also speak to the charity Invest in ME Research (IiMER) about their Centre of Excellence in the Norwich Research Park, and the other research charity ME Research UK. No British research strategy would be complete or effective without these other important players in the field. We would hope a similar collaborative process is taken within Australia working with patient stakeholders.

The IiMER Centre of Excellence for ME is of *national and international importance.* The proposal to establish a hub-and-spoke model UK Centre of Excellence for ME, based at Norwich Research Park with international cooperation, was published in May 2010 by UK charity Invest in ME Research. The work is now well underway, currently involving researchers based in Norwich, Oxford, Cambridge, London, Surrey, and in collaboration with other countries. For more information on this project see IiMER's executive summary here.

The allocation of research funds needs careful thought. Researchers previously involved in poorly designed, methodologically, or ethically flawed studies are not now going to become good, reliable scientists. Even if that were possible, they do not have the trust and confidence of the ME patient community. *Known proponents of the BPS model of illness in ME should not now be expected to produce, or be entrusted with producing, robust biomedical research.* This does not just include many Psychiatrists and Psychologists, but also some clinicians in other specialties such as Neurology.
The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK
[See links in *the unethical use of children.*]

Medical Education

As far as we can tell, the subject of *Myalgic Encephalomyelitis is completely absent in medical education* in the UK and Australia, at both undergraduate and postgraduate level. In its place, unhelpful clinical guidelines support the misconception that ME patients are simply lazy, depressed or deconditioned from lack of exercise. Our doctors thus have little understanding of the illness and its correct management.

Neither the RACGP, AMA, RANZCP, RACP, Royal College of General Practitioners, the Royal College of Physicians nor the Royal College of Paediatrics and Child Health currently mention ME in their postgraduate curriculums. Nor does ME feature in the undergraduate curriculum at the largest medical school in the UK, or in many medical schools in Australia. Instead, the Royal College of Paediatrics and Child Health supports Level 3 Safeguarding Training which includes lectures on safeguarding children with Chronic Fatigue symptoms and Pervasive Refusal Syndrome.

We are informed at the debate that the Royal College of General Practitioners (RCGP) does provide an online course on ME and CFS for GPs. One ME patient, a sick NHS Junior Doctor, checked this out for herself. She logged on and completed the module. Disappointingly, she reports that it is wholly inadequate and provides little real information. *As an ME patient, it left her with the feeling that it was written by people who have never met an ME patient in their lives.* This doctor states:

> **"***Really, the course is useless. GPs would do better just listening to their patients, and the RCGP would do better just pointing GPs in the direction of some good quality resources such as these:*
>
> Information for Healthcare Providers
> Myalgic Encephalomyelitis – Adult & Pediatric: International Consensus
> Primer for Medical Practitioners
> M.E. and Me: A Doctor's Struggle with Chronic Fatigue Syndrome
> Introduction to M.E by Dr Hng

[Addendum: In November 2018 a survey was conducted among higher specialty trainee physicians, to assess their knowledge and understanding of Myalgic Encephalomyelitis. 44 responses were received. The survey shows: "…errors in basic fundamental understanding, such as the *misconception that ME is partly or wholly psychological or psychosomatic.* It also highlights large deficiencies in education and clinical knowledge on ME, as well as *dangerous prevailing ideas on treatment.* Nearly all participants *(98%) believe ME can be treated with highly dangerous Graded Exercise Therapy.*" Doctors' Knowledge and Understanding of ME, UK 2018]

ME needs to be given a proper place in medical education. It should be in the Undergraduate curriculum, like other far less prevalent diseases. It should be in the Postgraduate curriculum for GPs, Physicians and Paediatricians, like other serious illnesses. All doctors must be able to recognise it regardless of specialty, given the variety of symptoms it can present with. Most importantly, *the content of medical education on ME should be developed in collaboration with:*

- Practicing ME physicians who take a biomedical approach towards ME.
- Medical professionals who have ME, some of whom also have qualifications and experience in Medical Education.
- **NOT Psychiatrists or Exercise Physiologists** who call themselves ME and CFS specialists.

Most importantly, governing and advisory bodies like ESSA, NHMRC, AHPRA and the RACGP must actively reeducate current specialists, doctors and allied health providers that GET and CBT not to be used or promoted as a viable or curative treatment.Governing and advisoring bodies must make sure that providers that actively continue these outdated treatments will face professional and legal consequences for knowingly putting their patients at risk.
[See attached file 'CFS-Discovery-Treatment-Document]

Appropriate and adequate specialist and community services and social support for ME patients

Currently many specialist CFS and ME clinics are led by Psychiatrists or Psychologists, and many are run by the providers' Mental Health departments. This is totally inappropriate for a serious and complex multi-system physical illness. *Such sick patients need to be managed by fully trained ME specialists.* Although such training and accreditation will take time to achieve, given that the condition does not even have a place in medical education in the UK let alone a specialist syllabus, specialist services can at least be led by interested Physicians (not Psychiatrists!) and those who are already treating ME patients using a biomedical approach, *rather than misinformed staff who disbelieve patients, blame them for their illness, and recommend harmful therapies.*

There are other issues that need consideration, such as appropriate inpatient care when ME patients are admitted to hospital, appropriately designed nursing home placements/housing where required, and adequate support for the severely ill who live at home, such as with self-care, shopping, cooking, cleaning, and in some cases tube feeding.

Appropriate and adequate care and support for children with ME

On the 7th of December 2018 the British Association for Community Child Health hosted Level 3 Safeguarding Training entitled, *"Navigating the minefield: Medically unexplained symptoms and FII"* for doctors and anyone in education, primary care or social work (FII probably stands for Factitious and Induced Illness). This training is approved by the Royal College of Paediatrics and Child Health (RCPCH) for five Continuing Professional Development (CPD) credits. Among the topics to be covered are safeguarding children with Chronic Fatigue symptoms and Pervasive Refusal Syndrome.

The ME community finds this extremely concerning, given the experience of many children with ME and their families thus far. Children with ME need proper recognition that they are seriously ill, not lazy. The *correct* diagnosis of ME needs to be made, not accusations of Factitious and Induced Illness (formerly known as Munchausen by Proxy), as is frequently the case. Children need to be given the *correct* medical treatments, which includes rest, and not forced to endure harmful treatments such as graded exercise, enforced "sleep hygiene", or be forcibly institutionalised and subjected to abusive "treatments".
False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis (ME)

ME/CFS and our children.

Voices from the Shadows

Their limitations in terms of school attendance and participation in sports need to be recognised and safely managed. Children need to be supported to gain *equal access to education* within the limits of their illness. Home schooling should be made a viable option, as well as remote attendance using a robot and Interactive Virtual Education. Simply forcing sick children to go to school, to the detriment of their health, is counterproductive.
How robots are connecting housebound children to the outside world | #CaseForChange

Nisai Group

The Young ME Sufferers Trust The Use Of Interactive Virtual Education For Young People With Myalgic Encephalomyelitis (ME)

The Tymes Trust has the best understanding of the needs of children with ME. We strongly urge the Department of Health and the Department of Education to collaborate with them on how best to provide for the needs of children with ME.

A social welfare system that works for ME patients

We are told that DSP/NDIA assessors have to take *“an evidence-based protocols' ' as* part of their training/assessment. Unfortunately we are as yet to procure an Australian copy of the Services Australia protocols but an example of a similar protocol in the UK can be viewed here. The NDIS Internal TAB document can be found here of the five documents and research articles the NDIS are relying on to make their assessments, only one was in date and scientifically relevant (the 2021 NICE review) all the other documents were either 10-20 years out of date or formally dismissed by cochrane as in their words “it predates the mandatory use of GRADE methodology to assess the strength of evidence, and the review is no longer current. It should not be used for clinical decision-making. The author team is no longer available to maintain the review."

Sadly, Services Australia and the NDIA *quotes the outdated 2007 NICE guideline* which is not fit for purpose and as we know, and has now been superseded by the UK’s 2021 NICE guidelines. On page 18 of the outdated 2007 guidelines it advises:

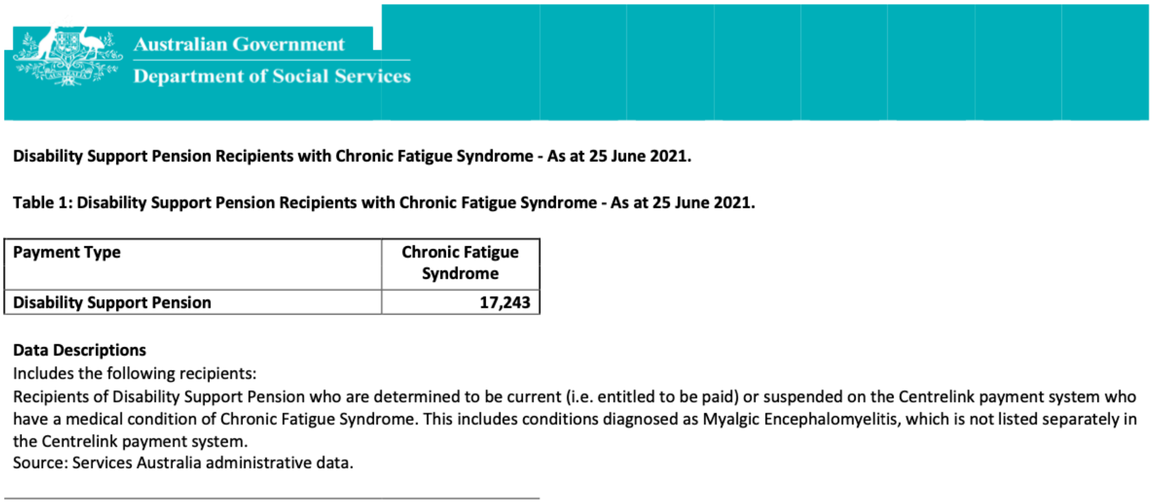
> *“Offer cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) to people with mild or moderate CFS/ME, …because these are the interventions for which there is the clearest research evidence of benefit.”*

The statement that CBT and GET have the clearest evidence of benefit is blatantly incorrect. (See above on the abuse of these treatments.) In fact, CBT and GET would be one way to give patients with mild or moderate ME severe ME instead! (NICE eventually agreed and stated in the 2021 guideline that the “evidence” for using GET and CBT as treatment options on ME patients was of “poor to very poor quality”.)

[Addendum: These critical reviews published in 2018 and 2019 provide evidence that CBT and GET cause significant harm in ME and produce no lasting benefit.
Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review.
Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective. Re-analysis of a Cochrane review.]

While the protocol advises that the variability in functioning of ME and CFS patients should be taken into account, in practice this is not happening, and patients are frequently denied the benefits to which they are entitled. Perhaps assessors need greater training on this point, or *perhaps they are somehow **incentivised** to deny claims.* Whatever the reason, the system is broken. *ME patients are regularly made worse by the demands of repeated assessments and appeals, left with little support, and some risk being made homeless.*

This freedom of information request from right to know, highlights this inequality and inaccessibility and clearly shows that in Australia of an estimated 250,000 patient group only a measliy **17,243** were eligible for the DSP.



Australian Government
Department of Social Services

Disability Support Pension Recipients with Chronic Fatigue Syndrome - As at 25 June 2021.

Table 1: Disability Support Pension Recipients with Chronic Fatigue Syndrome - As at 25 June 2021.

Payment Type	Chronic Fatigue Syndrome
Disability Support Pension	**17,243**

Data Descriptions
Includes the following recipients:
Recipients of Disability Support Pension who are determined to be current (i.e. entitled to be paid) or suspended on the Centrelink payment system who have a medical condition of Chronic Fatigue Syndrome. This includes conditions diagnosed as Myalgic Encephalomyelitis, which is not listed separately in the Centrelink payment system.
Source: Services Australia administrative data.

The system needs a radical overhaul if it is to serve the *very vulnerable* ME patients in the country. *The DWP and services australia must* work with the patient community and *appropriate* experts on ME to *produce a protocol and assessment system that is not only fair to ME patients, but avoids exacerbating their illness and worsening their disability.* Assessors must be completely impartial, with no possible conflict of interest between their role and their remuneration. The evidence used must be thoroughly reviewed, as we know that *so much of the "evidence" in this field is simply bad science.* The whole process must be made open and transparent, and any resulting protocol be made available for public scrutiny.

All assessments should be recorded in case of dispute. Any cases of dispute should be fairly reassessed under the new assessment system, free of any potential conflicts of interest, using methods that recognise the functional limitations of ME patients and do not further damage their fragile health. Due benefits should be repaid retrospectively.

[Addendum: In September 2019 a comprehensive review was published on Work Rehabilitation and Medical Retirement. Benefits assessors should take the findings of this review into account. It shows among other things, an overall dismal work status, and that *only 5% of patients recover. The prognosis in terms of returning to work is poor if patients have been on long-term sick leave for more than two to three years.* CBT and GET do not restore the ability to work. Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies]

In terms of the NDIS, there should be clearer access to services for those with ME and CFS. ME and CFS should be listed as a 'List B' permanent condition under the NDIS and listed as a condition eligible for DSP, public housing and SDA. Having community organisations and local area coordinators support those with ME and CFS to access the NDIS, DSP and other social supports actively is also important. There should be wider recognition of the condition to ensure people with ME and CFS are able to access supports. Health professionals that work with ME and CFS patients should also listen to those patients instead of questioning them.

The proposed independent assessments were also highly concerning for those with ME and CFS trying to access the NDIS as there are maybe less than 20 doctors in the country who understand ME and CFS. Therefore, how are assessments to be fair to those with ME and CFS when those doing these assessments lack any knowledge about the condition. Submission to the National Disability Insurance Scheme Inquiry into Independent Assessments

Additionally, not funding certain items on Medicare also increases the cost of living for those with chronic illnesses such as ME and CFS and there are so many barriers to accessing NDIS or DSP that would be able to aid with this. For example, sleep specialists, physios, occupational therapists, neurologists, general ME and CFS specialists and medications are not all under PBS or Medicare. 'The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort' found that "the mean annual cost of health care related expenditure and associated income loss among survey participants meeting diagnostic criteria for ME and CFS was estimated at $14.5 billion". The study concludes that “the economic impacts of ME and CFS in Australia are significant. Improved understanding of the illness pathology, diagnosis, and management, may reduce costs, improve patient prognosis and decrease the burden of ME and CFS in Australia.”.

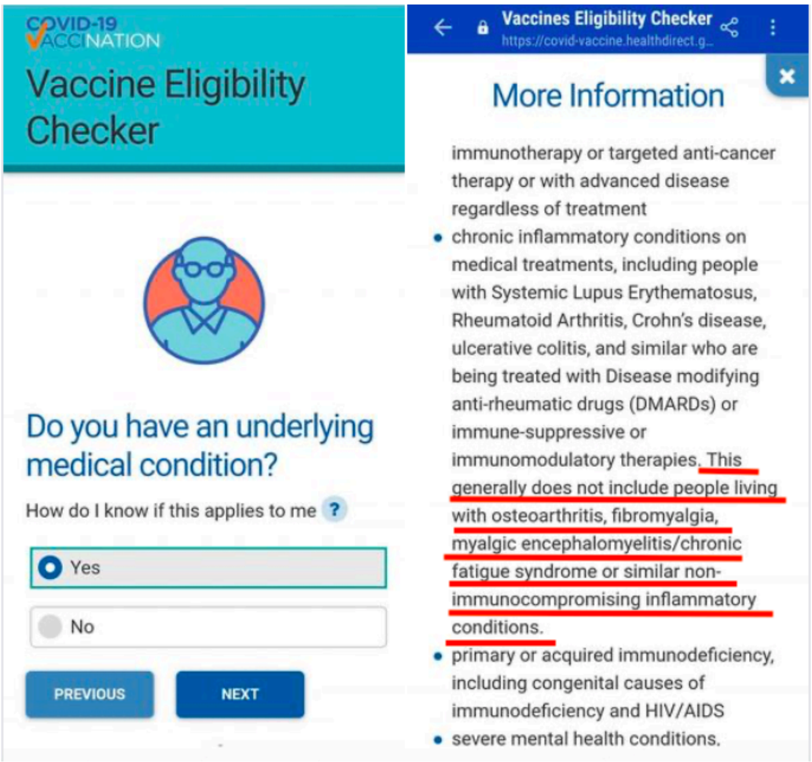
ME and CFS and COVID-19

There seems to be a higher incidence of people getting ME and CFS after having COVID-19 which validates what many people with ME and CFS have been saying for a long time, that the condition can be triggered by viral infections. If ME and CFS had been properly researched, we would have been better prepared for those experiencing ME and CFS from long COVID-19. Therefore, not funding the research has led to the current deficit in being able to support those with long COVID-19 and the wider ME and CFS community. This is compounded by the continued use of GET/CBT (which has been discredited to be used for treating ME and CFS) on those experiencing symptoms of long COVID. Thus, despite it being discredited for use to treat ME and CFS, it is now being used and marketed to those with long-COVID without any proper research. Therefore, it is costing us more now to retroactively respond to ME and CFS research needs than it would have if it had been properly funded to begin with. In addition to this, people with ME and CFS have both immunocompromising and immunosuppressing concerns but have been excluded from the high-risk categories of the vaccine rollout in Australia.

Surprisingly one of the authors of this document checked this for himself and although ME has unequivocal evidence of immunological dysfunction in ME/CFS and has been listed as a neurological condition on the **International Statistical Classification of Diseases and Related Health Problems** (ICD) code G93.3 since 1969. It appears the Australian Government had excluded people with ME from the vaccine rollout under both chronic neurological conditions AND Chronic Inflammatory conditions putting a high risk category of patients at risk of contracting Covid-19.

Ironically his own able bodied support workers were given priority access to the vaccine, although the Immunocompromised patient they are meant to support and protect could not qualify.

Recent reports from Australian Technical Advisory Group on Immunisation (ATAGI) have suggested that Immunocompromised people should receive a third booster shot “to maximise the level of immune response to as close as possible to the general population” It's still unsure whether ME and CFS patients will qualify for this much needed booster shot, federal health Minister Hunt has stated: “people who were only mildly immunocompromised were not yet being recommended for booster shots” but it's unclear at this stage who or what groups Minister Hunt and ATAGI will include or exclude in the booster rollout. Based on the evidence below it doesn’t seem very promising for patients with M.E.



Vaccine Eligibility Checker

Do you have an underlying medical condition?

How do I know if this applies to me ?

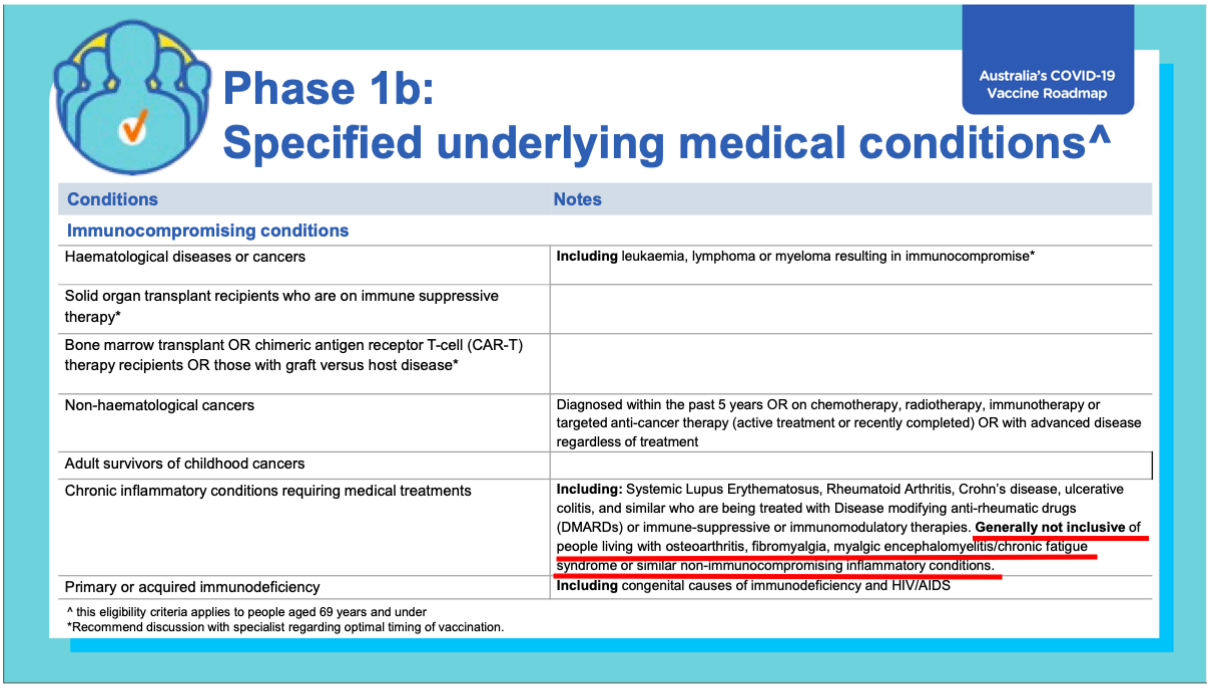
● Yes

○ No

More Information

immunotherapy or targeted anti-cancer therapy or with advanced disease regardless of treatment

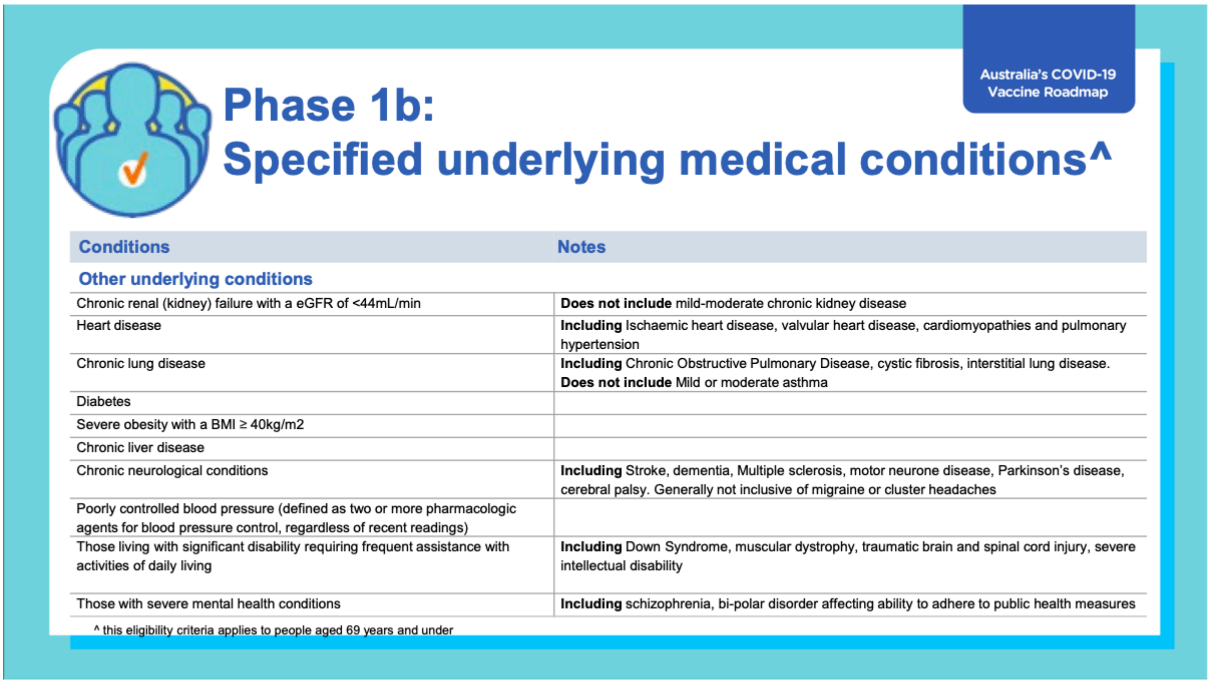
- chronic inflammatory conditions on medical treatments, including people with Systemic Lupus Erythematosus, Rheumatoid Arthritis, Crohn’s disease, ulcerative colitis, and similar who are being treated with Disease modifying anti-rheumatic drugs (DMARDs) or immune-suppressive or immunomodulatory therapies. This generally does not include people living with osteoarthritis, fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome or similar non-immunocompromising inflammatory conditions.
- primary or acquired immunodeficiency, including congenital causes of immunodeficiency and HIV/AIDS
- severe mental health conditions.



Phase 1b:
Specified underlying medical conditions^

Conditions	Notes
Immunocompromising conditions	
Haematological diseases or cancers	**Including** leukaemia, lymphoma or myeloma resulting in immunocompromise*
Solid organ transplant recipients who are on immune suppressive therapy*	
Bone marrow transplant OR chimeric antigen receptor T-cell (CAR-T) therapy recipients OR those with graft versus host disease*	
Non-haematological cancers	Diagnosed within the past 5 years OR on chemotherapy, radiotherapy, immunotherapy or targeted anti-cancer therapy (active treatment or recently completed) OR with advanced disease regardless of treatment
Adult survivors of childhood cancers	
Chronic inflammatory conditions requiring medical treatments	**Including:** Systemic Lupus Erythematosus, Rheumatoid Arthritis, Crohn’s disease, ulcerative colitis, and similar who are being treated with Disease modifying anti-rheumatic drugs (DMARDs) or immune-suppressive or immunomodulatory therapies. **Generally not inclusive** of people living with osteoarthritis, fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome or similar non-immunocompromising inflammatory conditions.
Primary or acquired immunodeficiency	**Including** congenital causes of immunodeficiency and HIV/AIDS

^ this eligibility criteria applies to people aged 69 years and under
*Recommend discussion with specialist regarding optimal timing of vaccination.



Australia's COVID-19 Vaccine Roadmap

Phase 1b:
Specified underlying medical conditions^

Conditions	Notes
Other underlying conditions	
Chronic renal (kidney) failure with a eGFR of <44mL/min	**Does not include** mild-moderate chronic kidney disease
Heart disease	**Including** Ischaemic heart disease, valvular heart disease, cardiomyopathies and pulmonary hypertension
Chronic lung disease	**Including** Chronic Obstructive Pulmonary Disease, cystic fibrosis, interstitial lung disease. **Does not include** Mild or moderate asthma
Diabetes	
Severe obesity with a BMI ≥ 40kg/m2	
Chronic liver disease	
Chronic neurological conditions	**Including** Stroke, dementia, Multiple sclerosis, motor neurone disease, Parkinson's disease, cerebral palsy. Generally not inclusive of migraine or cluster headaches
Poorly controlled blood pressure (defined as two or more pharmacologic agents for blood pressure control, regardless of recent readings)	
Those living with significant disability requiring frequent assistance with activities of daily living	**Including** Down Syndrome, muscular dystrophy, traumatic brain and spinal cord injury, severe intellectual disability
Those with severe mental health conditions	**Including** schizophrenia, bi-polar disorder affecting ability to adhere to public health measures

^ this eligibility criteria applies to people aged 69 years and under

On the other side, changes due to the current pandemic has seen a rise in accessibility for people with ME and CFS. For example

- Online formats (e.g., Video calls, telehealth) for classes, webinars, events, appointments etc.
- Increased social support such as more sessions under the Mental Health Care Plan
- NDIS funding for technology (for the few with ME and CFS that are currently able to access NDIS)
- Jobseeker/Jobkeeper increases that allowed people with ME and CFS to afford the specialist care they may have needed

Long Covid and ME

Recently we have seen in Australia an increase in "long covid" clinics, and while biomedical researchers have now found a strong link (below) between Long Covid and ME/CFS having the same calcium ion channelopathy dysfunction

Astounding links between Long covid and chronic fatigue

Unfortunately the treatments offered to these patients are the same abusive treatments that are offered to ME patients!, namely being graded exercise therapy and cognitive behaviour

therapy.
So what evidence are these clinics using? A reasonable person would expect there have been some empirical blinded study justifying/proving the use of these treatments. Yet these “Clinics” are relying on the same outdated, discredited abusive research that was justified for use on ME patients. Indeed I was quite surprised that the clinic that had abused me with GET and CBT were now offering it as a treatment/cure for long covid at the start of the pandemic!

ME and CFS and government policies

ME and CFS is relevant to the government, and changes have already been promised but not yet followed through, as shown in the following documents and groups:

Parliamentary Friendship Groups (non-country)
MISSING NO MORE: IMPROVING THE LIVES OF AUSTRALIANS WITH ME AND CFS
NHMRC Myalgic Encephalomyelitis and Chronic Fatigue Syndrome
Emerge Australia 2019-20 Federal Pre-Budget Submission

During a meeting at Parliament House, Health Minister Greg Hunt told ME Australia he was confident he could find between $6 to $9m for biomedical research into ME, unfortunately so far he only delivered $3m.
Australian government announces $3 million for medical research

It is recommended that all changes are guided and advised by people with ME and CFS.

There is also systemic use of diagnosis discrimination in government-led social programs such as the Companion Card program. ME and CFS are explicitly excluded based on their diagnosis from applying for a Companion Card. This is also seen in the NDIS (as described in Opinion: NDIS must recognise chronic fatigue syndrome or suicide will follow), housing (as described in Chronic Fatigue Syndrome – The Less Understood Condition In Home Care) and other social programs run by the government, where people with ME and CFS are excluded from accessing these programs only based on their diagnosis and outdated guidelines.

In summary, we need:

- An open and transparent protocol and assessment system that is fair to ME patients, recognises their functional limitations and does not further damage their fragile health.

- Completely impartial assessors, with no possible conflict of interest between their role and their remuneration.

- Thorough review of any evidence used. Only good quality evidence must be allowed. Simply quoting the UK’s 2007 NICE guidelines is no longer sufficient, nor should ME patients continue to be denied desperately needed social welfare for over two more years until the new guidelines are available.

- All assessments to be routinely recorded and made accessible to claimants, at no cost to them, in case of dispute.

- Fair reassessment of all cases of dispute and due benefits repaid retrospectively.

  - Public awareness campaign to reeducate researchers, medics, insurance agencies, allied health, the public and government departments on the validity and seriousness of the illness and be very clear it's not a psychosocial or somatoform disorder.

  - Patient/community lead input on guidelines or assessments that will directly affect us

Thank you. We look forward to continued progress on all aspects of provision for ME patients.

Yours sincerely,

Signed by: Insert current signatories to be contacted

Twelve ME and CFS organisations from the UK, Ireland, Europe, the USA, Canada and South Africa. Doctors, scientists, academics, patients, carers additionally signed the original UK version of this document created by Dr Robin Hng

Approximately **7898** other signatures also signed the original UK version of this document created by Dr Robin Hng, at: After the debate - CALL FOR CHANGE for ME patients

(this document has been edited to include an Australian perspective in addition to the UK perspective)

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