



MISSING NO MORE: IMPROVING THE LIVES OF AUSTRALIANS WITH ME AND CFS

THE GREENS PLAN WILL COMMIT TO:

- \$15 million funding for biomedical research
- A national ME and CFS Summit
- More funding for patient advocacy organisations
- Better access to the NDIS

Myalgic Encephalomyelitis and Chronic Fatigue Syndrome are complex, multi-system, biological conditions affecting between 100,000 and 250,000 Australians. Around 25% are so unwell that they are unable to leave home or bed, moreover, there is an estimated 5% remission rate. ME affects mostly women and girls. Between 70 – 85% of people with ME are female. It is a highly misunderstood and underrepresented area of medicine and this has had significant implications for patients.

The Greens understand and hear the frustrations of the ME and CFS community who have been of ignored, dismissed and ridiculed for too long. Patients and family members are routinely disadvantaged by social welfare and medical care systems which fundamentally do not understand the nature and effects of the conditions.

There is an urgent need for dedicated funding to biomedical research, and increased awareness by the medical profession and social welfare providers so that patients can get the support they need.

\$15 MILLION FUNDING FOR BIOMEDICAL RESEARCH

Australian scientists are leading the world in ME and CFS research. By funding biomedical research into ME and CFS, the Australian Government can improve diagnosis and treatment. Australia is in danger of losing the head start we have if we don't support homegrown research.

The Greens would create a \$15 million fund which would be administered by the National Health and Medical Research Council (NHMRC). This funding would enable Australia's ME and CFS experts to continue and expand research in areas such as:

- A diagnostic test for ME and CFS
- Understanding differences in metabolites
- Pharmaceutical trials for the identified calcium channel ion defects
- Identifying ways to improve the mitochondrial function of people with ME
- Genomics studies to understand how variation in a genotype relates to changes in the phenotype at the molecular or cellular level

NATIONAL ME AND CFS SUMMIT

For years patients have been denied care and have suffered discrimination due to outdated and poorly formulated medical guidelines. The NHMRC has established the ME/CFS Committee to look into research, identify research gaps, advise on status of clinical guidelines and requirements and opportunities for improved guidelines.

They are expected to recommend new guidelines and it is essential that these guidelines are followed, and that they form the basis of policy responses to support patients and their families.

To enable this, the Greens will convene a national ME and CFS Summit bringing together the patient advocacy groups, biomedical researchers, clinicians, and key government bodies including the National Disability Insurance Agency (NDIA), the Department of Human Services (DHS) and the Department of Social Services (DSS).

The agenda of this summit will be created by way of a process of codesign with patient advocacy groups. The goal of this forum will be to create a pathway towards patient-focused policy settings which support evidence-based medical treatment and social supports to enhance patient well-being.

MORE FUNDING FOR PATIENT ADVOCACY ORGANISATIONS

ME and CFS patients routinely experience poor treatment interacting with healthcare providers. This often occurs because of a lack of knowledge and awareness about ME and CFS in healthcare professionals.

Many patients are advised to undergo Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) even though evidence does not support these treatment methods.¹

To address this issue, the Greens will increase funding to ME and CFS peak advocacy organisations as part of our plan to boost disability advocacy funding by \$11.3 million over four years. This will enable patient advocacy groups to work directly with medical bodies to develop specialised training for practitioners and providers.

BETTER ACCESS TO THE NDIS

The NDIS was introduced to support and empower disabled people to access the supports and services they need. For people with ME and CFS there are

significant barriers to accessing this service that result from a system that bases its eligibility requirements on proofs of disability and permanency that are very difficult, if not impossible, to obtain for ME and CFS.

The Greens would ensure that NDIA access guidelines reflect the latest clinical understanding of ME and CFS, and properly fund the agency so that it is able to develop a dedicated ME and CFS participant pathway. This will enable ME and CFS patients to access the scheme with ease.

¹ The U.S. Centre for Disease Control and Prevention have removed all recommendations of GET and CBT. The National Institute for Health and Care Excellence in the U.K are reviewing their ME and CFS guidelines in light of a significant body of evidence which implicates the harms associated with this therapy combination. See "Treatment Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)", Centers for Disease Control and Prevention 2018, <https://www.cdc.gov/me-cfs/treatment/index.html>; "Myalgic Encephalomyelitis (Or Encephalopathy)/Chronic Fatigue Syndrome: Diagnosis And Management Guidance And Guidelines", National Institute for Health and Care Excellence, 2018, <https://www.nice.org.uk/guidance/ingid-ng10091>. Geraghty, "Further Commentary on the PACE Trial: Biased Methods and Unreliable Outcomes"; David F. Marks, "Special Issue on the PACE Trial," *Journal of Health Psychology* 22, no. 9 (2017): 1103–5, <https://doi.org/10.1177/1359105317722370>; Charles Bernard Shepherd, "PACE Trial Claims for Recovery in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - True or False? It's Time for an Independent Review of the Methodology and Results," *Journal of Health Psychology* 22, no. 9 (2017): 1187–91, <https://doi.org/10.1177/1359105317703786>; Keith J. Petrie and John Weinman, "The PACE Trial: It's Time to Broaden Perceptions and Move On," *Journal of Health Psychology* 22, no. 9 (2017): 1198–1200, <https://doi.org/10.1177/1359105317703789>.