

Transcript of ME/CFS Australia's Presentation to the Parliamentary Friends of ME/CFS 13 June 2023

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Thank you for the invitation to be here today.

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On 16th February this year, this family home was threatened by bushfire. Inside was Dan Harris, who has severe ME/CFS. He could not be moved.

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Dan's mother Lynne Harris said to me:

*If we could move Dan on those days when it's forecast catastrophic, then we would!
But moving him is not an option because of the potential harm it would cause.*

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This is Carmel Johnson, who had severe ME/CFS, and who died in March this year at the age of 28.

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Carmel's mother, Judith Anne Johnson said to me:

*People need to understand...
this is NOT about being chronically fatigued.*

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In 2014 Alem Matthees took a Freedom of Information request to Queen Mary University of London. The university spent quarter of a million pounds fighting Alem's request in the courts, which in 2016 found in Alem's favour.

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The released data enabled the research to be reanalysed, with findings that reflected lived experience. The global ME/CFS community owes Alem a great deal. The Australian ME/CFS community has been aware of the impact on Alem's health and gave him this small token acknowledging his selfless effort.

Alem... put his own health on the line to try and protect the health of others.

On Friday, Alem sat up on the edge of his bed for us, because ..

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He is desperate for people to really know what it's like having severe ME.

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Immunologist, Nancy Klimas, is a clinician and researcher in AIDS and ME/CFS.

...patients with this illness experience a level of disability that's equal to that of patients with late-stage AIDS...

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What are health practitioners supposed to do?

Australian clinical guidelines are 20 years out of date.

This means they are missing more than two decades of research.

Even when they were new, they were not well received and the South Australian Dept Health paid for new South Australian GP guidelines for ME/CFS to be developed with doctors and patients.

Missed diagnosis

It can take years to get a diagnosis. Even then, the vast majority of people with ME/CFS have not been diagnosed.

Misdiagnosis

At the same time, research indicates that many people with the diagnosis do not have ME/CFS.

The diagnostic criteria are clear and easy to use, but too many doctors are not familiar with them.

A common experience following diagnosis is to be told:

I'm sorry, but there's nothing I can do for you.

Yet there is a great deal that can be done to address the symptoms.

Again, lack of familiarity is a problem.

A key area of misunderstanding is the difference between Post Exertional Fatigue, Post Exertional Symptom Exacerbation and Post Exertional Malaise.

People with many chronic illnesses experience Post Exertional Fatigue, that is fatigue with is abnormal, different to a healthy person. There are multiple illnesses where people experience Post Exertional Symptom Exacerbation, for example their pain may be worse or their cognitive dysfunction may be worse after exertion.

However, Post Exertional Fatigue and Post Exertional Symptom Exacerbation disappear within 24 hours.

One of the characteristics of Post Exertional Malaise is that recovery is prolonged, with poorer health and increased disability during Post Exertional Malaise.

When I was in a study designed to provoke PEM, it took me 6 months to recover.

Alem Matthees has still not recovered from his exertions in 2014-15.

This difference in recovery is what exposes people with ME/CFS to harm from ill-informed clinicians.

Not understanding this difference leads to stigma and disbelief amongst health practitioners, which is communicated to partners, families and the wider public.

It results in false expectations of capacity and recovery.

New Australian clinical guidelines are urgently needed to address these issues.

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What can service and welfare providers do?

Again, the Australian clinical guidelines that they are using are 20 years out of date.

This leads to a misunderstanding of impairments.

Barriers to accessing disability and other services, including income support, are not recognised.

One in four people with ME/CFS is homebound, often unable to even access telehealth which requires annual face-to-face attendance for eligibility.

If you cannot access primary health care, you cannot get referrals.

If you do get a referral to a specialist, the number familiar with ME/CFS is low.

Waiting lists are long or even closed.

Without access to doctors and allied health professionals, you cannot get reports for access to services.

Service and welfare providers often require completion of inappropriate and discredited therapies as a condition of access.

And where permanency is a precondition for access, prospects for recovery are not consistent with the evidence.

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What are patients supposed to do?

What are they supposed to do when they cannot access primary health care?

Volunteers contacted 75 local GP clinics trying to find a GP to do a home visit for someone with ME/CFS, so as to establish telehealth eligibility. They could not find one GP to do a home visit.

What are they supposed to do when they cannot access knowledgeable clinicians?

Our member organisations are constantly being asked for names of doctors and allied health practitioners who understand ME/CFS.

What are they supposed to do when their impairments prevent them from successfully navigating access to services?

What are they supposed to do when their symptoms prevent them from complying with income support requirements?

For example, one common experience is losing access to income support because an in-person appointment has been missed.

Without current clinical guidelines to refer to, patients are left to advocate for themselves in the face of resistance and misunderstanding.

I've just outlined some of the significant challenges facing people with ME/CFS and facing those who seek to help them.

We do have a recent example of positive change:

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This year, significant changes to the Impairment Tables for the Disability Support Pension were passed into law, that positively affect people with ME/CFS. How did this happen?

The critical elements in this positive change for people with ME/CFS were:

The political will of the Senate.

The intention of the Department of Social Services

And the evidence from lived experience and research.

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To transform the lives of people with ME/CFS, what do we need?

The NHMRC ME/CFS Advisory Committee Report recommended new clinical guidelines in 2019. This year's Long Covid inquiry recommended action on the 2019 NHMRC Report's recommendations. Yet there was no money in the May budget for new Australian ME/CFS guidelines, even though the ME/CFS organisations were united in calling for it. What is happening?

\$1.5million would allow the convening of a working group of researchers, clinicians, and people with lived experience, drawing on the expertise of those in Australia who have been co-authors of international clinical guidelines. We have the expertise.

Research funding for decades has been minimal in comparison to the prevalence and economic burden and human suffering. Research underpins clinical guidance.

Pathophysiology studies can build on emerging evidence from ME/CFS, Long Covid and dysautonomia studies.

Clinical studies are urgently needed. For example, Low Dose Naltrexone and other repurposed and novel drugs.

Translational studies will allow application of evidence to impact everyday practice.

For example, the nurse-led model of care for ME/CFS in General Practice, that Bridges and Pathways have rolled out to over 20 practices in metropolitan and rural South Australia, are waiting on evaluation to allow rollout across the country.

Patients, their families, the researchers and clinicians who support them have been calling for change for decades.

However, ...

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...it all begins with the political will to drive change.

We know from other health challenges, such as HIV/AIDS or the Covid vaccines, that when political will is present, lives can change.

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What can **you** do?