

20 July 2015

Submission to the Inquiry on Chronic Disease Prevention and Management in Primary Health Care

Dear Standing Committee on Health,

The Quiet Crisis

I welcome this opportunity to make a submission about the scandalous underfunding of management, research and treatment for the 94,000 Australians with Myalgic Encephalomyelitis (M.E.).

Firstly, the disease M.E. should be properly distinguished from 'chronic fatigue syndrome' which is an umbrella term in Australia covering all manner of fatiguing conditions. M.E., however, has an internationally recognised definition (International Consensus Primer at **Attachment A**) and has been recognised by the World Health Organisation since 1969.

1. Examples of best practice in chronic disease prevention and management, both in Australia and internationally;

For examples of best practice, I refer you Norway. Norway's Prime Minister recently, in May 2015, apologised to patients for the way they have been treated.

The Norwegian Directorate of Health has also apologised for not having provided the necessary and proper health services to people with ME. (See <http://www.tv2.no/a/3618296> for the footage of the statement). It is time for Australia to offer the same recognition for people with M.E..

Norway recently funded a successful trial into Rituximab, a drug which targets B cells and is already used in Australia to treat lymphoma and leukemia, indicating M.E. is an autoimmune disease. (The study is at **Attachment B**.)

This exciting breakthrough news was heralded in *New Scientist* magazine, indicating its significance.

Funding into research is critical in furthering our understanding of M.E. and therefore our prevention, treatment and management. Currently research into M.E. (and chronic fatigue syndrome) is ABYSMALLY funded. In the past 16 years, the National Health and Medical Research Council has only granted \$2.1 million towards research (figures from 2015 letter from Minister Sussan Ley MP, Ref MC15-008596).

This equates to around \$131,000 a year. This is barely enough to pay for one scientist and part of an empty lab.

In the same period, AIDS received 50 times more funding (more than \$100 million since 2000 from NHMRC). Fewer than 35,000 Australians are HIV positive, far fewer than the 94,000 of us suffering from the immune disease M.E (figure from Emerge Australia, **Attachment C**).

A world-leading researcher told me my immune system is comparable to an AIDS patient so we need to increase funding into M.E. research by at least 50 times, we need \$100 million for this quiet crisis.

2. Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management;

No comments.

3. Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;

Opportunities for the Primary Health Networks exist to coordinate and support people with M.E. by helping organise support through home visits or Skype/teleconferencing (and for Medicare to recognise teleconference support) for housebound patients.

4. The role of private health insurers in chronic disease prevention and management;

No comments.

5. The role of State and Territory Governments in chronic disease prevention and management;

The role of State and Territory Governments in chronic disease prevention can play is to implement food safety, such as 'Scores on Doors'. In 2012, I was infected with an enterovirus, which is often the trigger for M.E.. Enteroviruses are spread by the fecal-oral route, so food handling hygiene is imperative. Please urge the ACT government (and other states and the Northern Territory) to improve food handling and implement 'Scores on Doors' so consumers can make informed choices about food safety.

6. Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management.

Regarding 'Innovative models which incentivise access, quality and efficiency in chronic disease prevention', please see my response under point 5 to find innovative ways to prevent M.E.. If the person preparing my food had washed their hands properly after going to the toilet, I would still be in full-time work, instead of housebound with a shortened life expectancy.

7. Best practice of Multidisciplinary teams chronic disease management in primary health care and Hospitals; and

8. Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

Unfortunately, I am a frequent user of medical services and I see a need for education of general practitioners in the latest research into chronic diseases. I have received contradictory advice (and potentially dangerous) advice. Thankfully I did see specialists at Griffith University's National Centre for Neuroimmunology and Emerging Diseases who understood the condition better. Out-dated suggested therapies for 'chronic fatigue syndrome' such as graded exercise therapy have proved harmful for people with M.E, yet that message hasn't reached all medical practitioners yet.

For a complex multi-system chronic disease such as M.E., GPs require the support of specialists on occasion. Specialists are frequently unwilling to see chronic disease patients as they think there is nothing they can do to help us. That is not true. While under current treatment regimes in Australia we cannot be 'cured' in most cases, their expertise can help us understand and manage our chronic illnesses better, as well as rule out other diagnoses. This leads to a better quality of life and engagement in the workforce and community (and less reliance on healthcare in the long term), as well as fewer visits and less burden on primary care. Specialists, such as immunologists, endocrinologists, neurologists and general physicians, need to be part of a multi-disciplinary team and encouraged to consult with GPs about patients with M.E..

In closing, thank you for this opportunity to contribute to the enquiry. It is very difficult to be in my 30's, healthy and able to work long hours as a federal ministerial media adviser, then for it all to change by simply catching a virus which devastated my immune system and now being mostly bed-bound, always in pain, reliant on others to cook, shop for food, clean and care for me.

Attachment A: International Consensus Primer for Myalgic Encephalomyelitis 2012 (PDF document)

Attachment B: B-Lymphocyte Depletion in Myalgic Encephalopathy/ Chronic Fatigue Syndrome. An Open-Label Phase II Study with Rituximab Maintenance Treatment, Øystein Fluge, Kristin Risa, Sigrid Lunde, Kine Alme, Ingrid Gurvin Rekeland, Dipak Sapkota, Einar Kleboe Kristoffersen, Kari Sørland, Ove Bruland, Olav Dahl, Olav Mella. Published: July 1, 2015. DOI: 10.1371/journal.pone.0129898 (PDF document)

Attachment C: 'ME affects 94,000 Australians' from Emerge Australia (PDF document)