This is a letter template to help you write to politicians and bring attention to the issue. Use it as a guide to create your own letter, remove or add parts as you wish. Now is the time to write, before this year’s federal election!

As you write your letter, consider asking for what you need, tell your story and tailor it to the minister/shadow minister you are writing to. Are you most concerned about funding for medical research? Education for doctors? Personalise: Talk about your life before your illness: What was your career? Could disability services enable you to do some work? Did you have/are you having education difficulties that the minister could help with? Are you a veteran? Do you need help with housing? Have you had trouble accessing suitable health services (ie GP home visits). Do you need care? This will help you determine who to send it to; either via your local member or to the minister/s responsible for the area.

You might consider writing to federal election candidates in your area and ask them what they would do to help people with ME or CFS if they were elected. You may ask them to take the ME Chilli Challenge or to visit you at home to see the extent of your illness.

Personalising the letter will make it more likely to be read and have an impact, so if there are any other issues or questions you have, include them in the letter.

Here’s who to write to & how to contact them:

Federal senators and members:
http://www.aph.gov.au/Senators_and_Members/Parliamentarian_Search_Results?expand=1&q=&mem=1&par=-1&gen=0&ps=100&st=1

South Australian Parliament:
https://www.parliament.sa.gov.au/Members/HouseofAssembly/Pages/ContactDetails.aspx
Western Australian Parliament:
Dear (local federal/state/territory member)
(federal MP or senator)
(federal health minister or shadow health minister)
(federal disability/housing/social services/ageing/medical research/veterans’ affairs/education)
(state or territory MP)
(state or territory health minister or shadow health minister)
(state disability/housing/social services/ageing/medical research/veterans’ affairs/education)
(candidate)

I am one of the 96,000 Australians living with Myalgic Encephalomyelitis or ME (or I am one of the 242,000 Australians with chronic fatigue syndrome or your diagnosis). (here you may wish to write about your circumstances for example, I was xx years old when I fell sick after contracting glandular fever/Coxsackie virus/Q fever/Ross River fever etc)

Our illness is an issue of national significance.

According to the National Health and Medical Research Council, the federal government has not funded a study into chronic fatigue syndrome for more than a decade, since 2005. Only two studies have been funded since 2000, a total of only $558,000 in 17 years (and one of these studies was only relevant to Gulf War veterans). The Department of Health just admitted it overstated the funding and submitted new figures, revealing an even worse situation.

Compare this to another immune illness, HIV, which has received more than $100 million despite having a much smaller prevalence in the population. (There are around 26,000 people living with HIV in Australia.)

ME costs the Australian economy $4 billion in lost earnings every year. We have had very little help, not enough biomedical research and don’t even a national body to represent us like the Cancer Council, MS Society or the Heart Foundation. I ask for your urgent attention to help me and others like me.

In Norway, scientists have had some success treating ME/CFS with the immune-modulating drug Rituximab (used in Australia on leukemia patients). Their Prime Minister and their Department of Health recently apologised to patients with ME, saying “we have not established proper health care services for these people, and I regret that.”

Scientists at USA’s Columbia and Stanford universities and Australian scientists at Griffith University have found significant immune problems and identifiable immune signatures.
Griffith University researchers have just patented a diagnostic blood test, bringing us closer to understanding the illness, but this cannot happen without funding.

Dr Lipkin, Columbia University, believes if the appropriate financial resources were thrown at the problem, we could have treatments for ME/CFS in five years.

I ask for equitable research funding for this painful, debilitating illness.

I ask for your help to ask the NHMRC fund medical research into the illness, using the latest International Consensus Criteria for Myalgic Encephalomyelitis (2012) and looking at the leading international research, perhaps contributing financially to an international study? (if you are writing to a state or territory representative, consider changing this paragraph to services your state could provide)

I ask for doctors and medical professionals to be educated. Australia’s Emerge and the UK’s ME Association warns against how harmful exercise can be. Despite that, some Australian doctors are still using that outdated information, so we also need help educating doctors on the latest immune findings. How can we educate doctors and other medical professionals?

(here you may wish to add more about yourself, ie ‘It took me xx years/months to receive a diagnosis. I received helpful/unhelpful/outdated information’. You may want to add a short sentence about before illness: Instead of earning xx as a xx, I am now reliant on xx. I was involved in my community as a coach/volunteer/helping local school/in a band etc)

(Optional or adapt to your preference) Could you also fund Emerge Australia to represent us nationally, like other illnesses are represented? They’ve done amazing work to help me yet they receive no federal or (insert your state, NSW/QLD etc) funding.

On May 12, International ME Awareness Day, will you wear a blue ribbon to show your support for people with the illness?

(Include any other concerns you have about housing or care, or concerns even if they aren’t about ME or CFS, for example NDIS, cuts to CSIRO, environmental laws, tax reform, ministerial code of conduct, education, foreign aid or trade, the introduction of laws on approving marijuana for pain relief etc)

I look forward to hearing from you.

(name)

You may wish to enclose some of these articles, depending on the content of your letter:

http://www.meaction.net/2016/02/12/australian-health-department-pins-its-hopes-on-nih-research/