

Submitted to About the Act and Code Review  
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I've been really lucky to have understanding GPs for the last ten years or so, but even then, I have had to be the driver for my trials and treatments. I've

had to do my own research and produce treatment plans that the GPs can work with, as they don't have the time or resources to do it themselves. (There are also plenty of people around the country who are less fortunate, who don't have helpful GPs and even still some who are not believed, which is just unacceptable.)

There are also no specialists I can get referred to -- I briefly saw a cardiologist in Wellington who 'had an interest' in ME/CFS, but my GP spent six months trying to get me back in for a follow up with no success.

I've recently started seeing a private lifestyle doctor, who immediately diagnosed me with Hashimotos and various other issues that the GPs hadn't picked up because of the obscure way 'acceptable ranges' for blood tests are interpreted. This is something that desperately needs to change. The fact that I might have had these underlying issues on top of the ME/CFS for twenty years, with no diagnosis or treatment, is really depressing.

New Zealand desperately needs to up its game on the ME/CFS front. Dr Warren Tate has been doing some great work on the research front, but where are the specialists, the facilities, the assistance we so desperately need? One of my biggest problems in getting help is that I'm only 'disabled' sometimes. When I crash it can be for a year or two, I can barely make a cup of tea, never mind anything more than that. But then in remission I regularly run 5k. We need a system that understands life isn't linear -- and neither is disability.

Thank you for taking the time to read my submission.

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Not Answered

## Topic 1: Supporting better and equitable complaint resolution

1.1 Did we cover the main issues about supporting better and equitable complaints resolution?

Please add your response below:

1.2 What do you think of our suggestions for supporting better and equitable complaint resolution, and what impacts could they have?

Please add your response below:

1.3 What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaint resolution?

1.3 changes - supporting better and equitable complaint resolution:

## Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

3.1 Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?

Please add your response below:

3.2 What do you think of our suggestions for making the Act and the Code work better for tāngata whaikaha | disabled people, and what impacts could they have?

Please add your response below:

3.3 What other changes, legislative and non-legislative, should we consider for making the Act and the Code work better for tāngata whaikaha | disabled people?

Please add your response below:

## Publishing and data protection

May we publish your submission?

Yes, but please remove my name/my organisation

Please note any part(s) of your submission you do not want published::

You are welcome to publish my submission, but please don't publish my name or personal details. Thanks.

Reasons to withhold parts of your submission

Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.:

Yes

I think these parts of my submission should be withheld, for these reasons: :

As this is essentially personal health information, I would ask my personal details are withheld.

If needed, can we to contact you to follow up for more detail on your submission?

Yes, you can contact me

Would you like to receive updates about the review?

I'd like to receive updates about the review