Response ID ANON-C5F6-7W21-5

Submitted to About the Act and Code Review
Submitted on 2024-07-31 11:36:08

Your details

1 What is your name?

Name:
[redacted]

2 What is your email address?

Email:
[redacted]

3 Are you submitting as an individual, or on behalf of an organisation or group?

I am submitting as an individual

4 How did you hear about this consultation?

Select from the following options:
Social media

If you selected other, please specify below:

Questions for individuals

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Share ‘one big thing’ or upload a file

5 Are you here to tell us your ‘one big thing’?

Your one big thing::

Whether one has M.E., Long Covid, or any disabling auto-immune disease and co-morbidities - there is NO support. My GP doesn't even know what M.E. stands for. (He once told me I need a 'Shaman'. ??) As a result, people like me are treated as mental health patients and have to suffer not only the dire consequences of the disease - loss of career, ability to work, family and friends who invariably don't understand, a social life, a meaningful existence, but also the stigma the health system imposes on us.

We live with daily joint and muscle pain, crippling fatigue, nausea, vertigo, IBS, migraine and headaches, tinnitus, to name but a few of multiple and regularly concurrent symptoms. When PEM occurs it is sudden and utterly disabling. Yet the attitude of most is that we must get out more. I often cannot get out of bed. Normally a very tidy and clean person, my house is now filthy as I can't clean it and my personal hygiene is compromised too. As for cooking and laundry, well once in a while I might be able to rustle something up but often it's muesli for dinner, and I get undressed in front of the washing machine and dressed in front of the dryer - IF I have been able to put a wash on.

I am astonished, dismayed and utterly perplexed as to why our health system has completely forgotten or chosen to be wilfully ignorant of all of us. It has driven me to end-of-life options and so dramatically affected my life that I cannot imagine a future that is not without suffering and hopelessness.

The health system is screwed right now, let's face it, we all know that. But at the very least, I thought when this whole nightmare started 5 years ago that someone would help. Something would happen.

Nothing and no-one does. And it's not just me - joining support groups and pages has confirmed that virtually every member is in the same leaky boat.

So my overwhelming concern is: Why are we suffering with no help? Why does the system and WINZ not recognise our disease? And why is there no one (in Wellington at least) who specialises in M.E. that is available to all?

Because I wouldn't wish this catastrophic condition on anyone.
It's that severe.

6 Upload a file

File upload:
No file uploaded

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:

Include M.E. and sever auto-immune disease sufferers. They are genuinely disabled people too.

Topic 5: Minor and technical improvements

5.1 What do you think about the issues and our suggestions for minor and technical improvements, and what impacts could they have?

Please add your response below:

5.2 What other minor and technical improvements, both legislative and non-legislative, should we consider?

Please add your response below:

5.3 What are your main concerns about advancing technology and its impact on the rights of people accessing health and disability services?

Please add your response below:

5.4 What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

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::

Reasons to withhold parts of your submission

Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.:
No

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

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, I'd like to receive updates from the HDC about this and other mahi