

6/08/2024

Act and Code Review Feedback Session

Andrew Barron

HDC attendee: Jane Carpenter

Introduction

Andrew shared his story:

Andrew started in community work in the 1980, has worked for the Hon Sandra Lee and PPTA. Had to leave employment of PPTA because of ME / Chronic Fatigue Syndrome after having an adverse reaction from a flu jab.

The PPTA had an insurance policy for staff (with the relationship/policy being with PPTA rather than me). Was initially sent to a Dr by the insurance company and was told I couldn't be assessed until seen by a psychiatrist or psychologist, and was told to undertake graded exercise therapy and CBT. It is well established that chronic fatigue syndrome is not a psychological illness and CBT is not a treatment for chronic fatigue. Graded exercise therapy can aggravate disability from chronic fatigue syndrome and cause harm.

Andrew put in a complaint to HDC in Jan 2020. HDC responded that it was not going to take further. Andrew went to the Ombudsman and in June 2021, the Ombudsman found that the assessment of the complaint was unreasonable, and also referred to the Insurance and Financial Services Ombudsman who did not look at the complaint because the policy was held by the PPTA. The Ombudsman recommended that Andrew resubmit the complaint, which he did, as well as raise matters with the Insurance & Financial Ombudsman. Since Andrew's initial complaint he has met many others with chronic fatigue syndrome who struggle to self-advocate, and he feels he has a duty to make this submission not just for him but for others who struggle to have a voice.

Information about chronic fatigue syndrome

Andrew shared information about chronic fatigue syndrome:

- Chronic fatigue syndrome, including long COVID is the fastest growing disability in the world and a large number are affected.
- However, NZ does not keep statistics, there is no specialised training, no specialised services etc on chronic fatigue syndrome.
- The majority (around 75%) of people with chronic fatigue syndrome are thought to be women, generally late 20s to middle age, although this may be because chronic fatigue is masked in older age, and governance truancy programme has not looked at long covid in children. It affects all ethnicities. Challenges with particular cultures and intersectionality particularly where traditional family roles cannot be performed. Should be the priority illness in terms of numbers and effect.
- Highly stigmatised illness. Seen as lazy. 25% of people with chronic fatigue syndrome cannot work, or do tasks such as drive. Suicide rate is 6x average suicide rate.

Matters relating to the insurance company

Andrew shared that the Insurance and Financial Ombudsman will not take his complaint because the policy is with PPTA not him. He raised concerns about how the insurance industry was using medical practitioners to stifle claims. Andrew also raised concerns with the Medical Council because there is no known effective treatment for chronic fatigue syndrome, so declining claims because of not undergoing ineffective and potentially harmful treatments was not reasonable. The clinical assessment should be about the ability to return to work, depression could be a comorbidity, but should not be the focus of the assessment.

The clinician who undertook original assessment has since agreed that Andrew is not fit for work, but have still not received a payment from the insurance company.

Andrew's resubmitted complaint and action asked of HDC

In resubmitting his complaint, Andrew asked the Commissioner to use her power under s14(1)(d) to make a statement that:

- graded exercise therapy is harmful and should not be put forward for treatment for ME/Chronic Fatigue
- CBT should not be offered as a treatment for chronic fatigue syndrome; and
- that chronic fatigue syndrome is not psychiatric or somatic, it is a physical illness.

At the time Andrew resubmitted his complaint, WHO and most international regulatory agencies, as well as the information on health navigator agreed with those points. The NICE guidelines did not but were being reviewed and updated for chronic fatigue syndrome. By 2021, the NICE guidelines were also aligned that graded exercise therapy should not be put forward as a treatment or cure and were clear that chronic fatigue syndrome is a physiological illness not psychiatric illness.

The outcome of the resubmitted complaint was that the Commissioner chose not to make a statement.

Concerns relating to HDC processes and use of clinical advisors

Andrew raised concerns about the clinical peer review sought by HDC to advise on his complaint. Andrew considered that the peer review that HDC undertook was unsuitable – the use of non-treating Drs, particularly psychiatrists when chronic fatigue syndrome is a non-psychiatric condition being discriminatory and prejudiced. Andrew also raised concerns about social media posts made by one of the experts, and felt that these concerns were ignored.

Andrew advised that Official Information Act requests revealed that at no stage of the complaint process did the Commissioner receive expert advice about chronic fatigue syndrome. In Andrew's view the Commissioner would understand his complaint if she talked to someone with expertise, and while experts are limited, they do exist in NZ.

Andrew stated that the Commissioner upheld that it was acceptable to have a non-treating expert provide expertise on non-psychiatric issues because in her view the evidence on chronic fatigue syndrome was not clear, despite the NICE guidelines being updated.

Andrew felt that the focus of HDC from the beginning was on liming the complaint and finding ways to not investigate where they could get away with not investigating. When he raised concerns with HDC about their processes he was told he was distressing staff.

Andrew shared that the complaint process for people with chronic fatigue syndrome is hard to access because of its reliance on written correspondence. Throughout the process, Andrew's health suffered any time he tried to write something – post exertion malaise.

Action Andrew would like to see

Andrew expressed his concern at ongoing harm through the disabling medical practice of graded exercise therapy for people with Chronic fatigue syndrome. Exertion for people with chronic fatigue limits oxygen to the brain. Is the equivalent of water torture for healthy people. Andrew expressed that the Commissioner's decision not to prioritise making statements is not moral as the Commissioner has the discretionary ability to prevent and stop harm. The decision to not take action is viewed by Andrew as his sector being deemed as not being worth harm prevention.

Andrew would like to see:

- The Commissioner use her power under s14(d) to make the requested statements regarding chronic fatigue syndrome to prevent further harm – it is unknown how many Drs are still prescribing graded exercise therapy
- The allegations of inappropriate social media posts by an expert advisor taken seriously.
- Statistics collected on the prevalence of chronic fatigue syndrome and long covid.

Next steps

Jane advised that a copy of the notes taken at the meeting will be sent to Andrew for his review within the next week, and following his review and with his permission the notes can be used as a submission to the Act and Code review.

Jane committed to share this discussion with the Commissioner and leadership team and provide an update later in the year.

Andrew gave his permission for the review team to access his file as is necessary to understand and respond to the matters raised in this meeting.

POST SCRIPT COMMENT FROM ANDREW FOLLOWING REVIEW OF NOTES:

The only issues that does not seem to be emphasised is my heavy criticism of the Commissioner's process of only using 'peer' medical opinions and not seeking or receiving expertise regarding the illness concerned. In regard to ME / CFS she has deliberately refused expertise in ME / CFS and ignored submissions in relation to ME / CFS. This is deliberately allowing a culture of suggesting that there is not sufficient information about ME / CFS and that practitioners are operating in some sort of grey zone. This is not the case. The Commissioner deliberately sought peer opinion by a psychiatrist despite the complaint that this should not be seen by psychiatrists. In this, the Commissioner knowingly released my medical information to a practitioner that has no connection to my illness. This is disgraceful on a number of grounds.

Limitation to peer opinion drastically leaves health consumers vulnerable. My complaint was about the mishandling of ME / CFS by the health profession. Without seeking or receiving expertise in ME / CFS the HDC cannot understand or provide the appropriate protection. The Commissioner went on to suggest that ME / CFS is little understood without having received appropriate advice and then suggested that ME / CFS is an illness that psychiatrists may have an involvement with based on a single line from the psychiatrist that he believes there is a role for psychiatrists. He does not state what this role is, does not clarify whether this is regarding comorbidity and does not relate this to the role of the non-treating practitioner doing evaluation for the insurer as a third party. For her to come to a conclusion which effects 20 – 40,000 New Zealanders without any firm and robust medical support is simply a disgrace and should be disqualifying.

The other issue that could be strengthened is that the Commission introduced a prioritisation system and posted it on the website. She did not allow complaints already before the HDC to be put in that prioritisation system. This meant that the harm against those with ME / CFS was effectively deprioritised in relation to new complaints. The harm to my sector was deliberately pushed back by the maladministration of the Commissioner.