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Committee Secretary

Mental Health Select Committee

Parliament House

George Street

Brisbane Qld 4000

From:

Justine Lawson

Please do not publish my contact details. As you hopefully will understand, this area is contentious and difficult and I don't wish any random person to get my email or phone number off the published submissions. Thank you.

Ph: [REDACTED]

Dear Committee Secretary

Re: Submission to the Mental Health Select Committee
Inquiry into the opportunities to improve mental health outcomes for Queenslanders

(e) the mental health needs of people at greater risk of poor mental health;

I am writing to the Inquiry into the opportunities to improve mental health outcomes for Queenslanders to let you know about a situation that is common among my peers – people with the multi-system physiological illness Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). We are in the situation that people with Multiple Sclerosis were in a few decades ago, when they were diagnosed as having a psychiatric illness 'hysterical paralysis'. Although ME has been recognised by WHO as a neurological disease since 1969, unfortunately, a psychiatric framing (that the illness is maintained by false illness beliefs and fear of activity, and that subsequent deconditioning is the cause of physical symptoms) still holds sway in the majority of doctors' minds in all specialities as well as GPs. The NICE guidelines (UK) have recently been updated to reflect the current evidence, which shows that the belief that the cause of ME/CFS is psychiatric or psychological is, in fact, baseless. The CDC in the USA and others around the world are gradually catching up with the research that shows that this illness is complex and of a biological basis. The Canadian Consensus Criteria were already current with the actual evidence in 2002, and the International Consensus Criteria in 2012. The current pandemic is causing 'long Covid' in substantial numbers, some forms of which are remarkably like ME/CFS. Unfortunately, some doctors and psychiatrists are again labelling this as some kind of maladaptive mental disorder. I deeply hope that we've come far enough in our understanding of ME/CFS that this misinformed opinion won't gain widespread traction and cause considerable harm in another whole cohort of people.

The problems caused by doctors not understanding ME/CFS are numerous and have severe impacts on patients' mental health as well as their long term physical health, and all the flow-on social problems from having severe ill health. This obviously also affects the patient's family members

wellbeing and mental health.

So, when looking for opportunities to improve mental health outcomes for Queenslanders with ME/CFS, firstly a correct diagnosis is essential. This is in two parts. 1. A person who has ME/CFS is actually diagnosed with ME/CFS, not depression or anxiety or health anxiety or somatisation or treatment resistant depression or false illness beliefs etc. 2. When doctors do give the diagnosis of ME/CFS, they understand the actual complex nature of the illness' multi-system physiological abnormalities.

When people are left without a timely diagnosis, are misdiagnosed with a psychiatric condition, or get a diagnosis of ME/CFS where the doctor thinks the illness is a type of depression, the doctor usually prescribes behavioural changes as if they were treating deconditioning and depression. The ME/CFS patient undertaking such 'treatment' becomes worse because of the problems with their energy production and energy use systems. When people with ME/CFS push themselves to do more than can be metabolically supported, their symptoms all become worse and they take a greatly increased time to return to their usual level of illness from even minor tasks such as grocery shopping or showering, taking days, weeks, months, and sometimes never, depending on the level of challenge to their system. This situation becomes extremely damaging when the doctor does not believe the patient's report of their experiences and pushes the patient to repeat the damaging exertion again and again. Unfortunately, this damaging experience is very common and almost everyone who has eventually been eventually correctly diagnosed with ME/CFS has been through some form of this experience first. Another part of this mistreatment is when Cognitive Behaviour Therapy is used to try and change the patient's beliefs about their symptoms, causing the patient and their family a great deal of confusion and angst as the patient's beliefs are not mistaken at all. This is an unintentional but no less damaging form of gaslighting by the doctor.

The flow on effects of misdiagnosis or misunderstanding of the diagnosis on the part of the doctor, and therefor mistreatment of the patient, not only causes physical harm, it creates a great deal psychological harm and trauma. It creates misunderstanding and mistrust between the patient and everyone around them, often causing relationship breakdowns, divorce, loss of family, loss of property, loss of income, poverty etc.

People with ME/CFS often find themselves in need of Centrelink support, however, without accurate reports and support from their doctors, accessing this becomes a massive hurdle in itself.

Here is an opportunity to reduce the mental health trauma that continues to be inflicted on this patient group, sadly, by the medical system itself, and then by the community as a result. The current estimate is that 240 000 Australians have ME/CFS. Development of a Statewide ME/CFS HealthPathway with Queensland Health is underway and the National Advisory Advocacy Council for ME/CFS Research (NAAC) Chairperson Kathy Dallest, a consumer subject matter expert, is involved. I expect this HealthPathway to be a source of information that can be relied upon with confidence. This HealthPathway should be ready soon. HealthPathways provides all health practitioners, including mental health practitioners, with information that can help them keep up to date on current research, best practice and clinical guidelines on early diagnosis and management of ME/CFS to give their patients the best possible outcomes possible.

Another opportunity to improve mental health outcomes for people with ME/CFS is to educate doctors of all specialities to differentiate this illness from a mental illness. After correct diagnosis, people with ME/CFS often consult doctors for specialist advice about part of their ME/CFS illness eg cardiologist, immunologist, sleep specialist. Many of these doctors hold the misunderstanding

that ME/CFS is largely a mental illness and they give advice outside their field, as if they are trying to help someone with depression. It also means the doctor often downgrades the importance of the physical symptoms that they were being consulted about, and doesn't give them the attention that they should. This is devastating to the patient who has used up considerable amount of their physical energy resources to consult with this doctor only to be misunderstood, neglected or mistreated and dismissed, adding to their mental health burden.

And then there are the mental health aspects of having a chronic, disabling illness with no cure and only 5% recovery rate. People with ME/CFS need mental health support to cope with living like this and help with negotiating through life with extreme limitations on their abilities, as well as dealing with the trauma and stigma caused by disbelief, neglect and mistreatment by the medical system and doctors, and the flow on effects with family and workplace relationships, poverty etc. However, very few mental health workers have sufficient understanding of chronic illness and ME/CFS in particular to be helpful. Most seem at a loss, at best, and many give harm inducing advice that's more suited to depression and anxiety. They don't seem to be able to differentiate between a person feeling legitimately anxious about very difficult and threatening situations caused by their ill health (eg homelessness, relationship breakdown), and the person having anxiety as an illness. They have trouble differentiating between someone feeling depressed and grieving all the losses they are facing because of having ME/CFS, and a depressive illness that causes losses. An opportunity for improving the mental health of people with ME/CFS would be to educate those practitioners within the mental health field (psychiatrists, psychologists, nurses etc) about chronic, very long term illness and how to support the mental health of people in these difficult and often devastating, situations.

Another opportunity is to make this kind of mental health support, eg psychologists, available to people with ME/CFS without requiring them to get a mental illness diagnosis first. Imagine the mental pain caused when someone has had to fight through misdiagnosis of mental illness and the associated mistreatment and flow on impacts to get their physiological illness diagnosed properly, only to be required to then have a mental illness to get psychological help.

This help also needs to be affordable. Most people have lost a considerable amount of income and many rely solely on the Disability Support Pension or other Centrelink payments because of having ME/CFS, which means many people with ME/CFS don't have the means to pay for services, or for the gap payments in Mental Health Plans through Medicare.

Limits on how many sessions per referral under the Mental Health Plan system (currently 4 on one referral then another 6 requiring another GP visit per year?) is also a drain on the person with ME/CFS's energy and financial resources, not to mention a waste of the GP's time. The NDIS is exceedingly difficult to access for people with ME/CFS because of the way the NDIS works, not because they are "not disabled enough".

In summary, the opportunities to improve the mental health outcomes of Queenslanders with ME/CFS:

1. Educate Psychiatrists and GPs about what ME/CFS actually is and what it is not.
2. Educate doctors to be able to accurately diagnose people with ME/CFS.
3. Educate other specialists to understand ME/CFS, so they don't give mental health advice outside their speciality and so they take the physical symptoms seriously.
4. Educate mental health practitioners specifically how to support the mental health needs of people with a life-changing, energy limiting, chronic illness, ME/CFS in particular.
5. Make mental health support with psychologists easily available for people with ME/CFS. Eg

If under the Mental Health Plan Medicare system, increase the number of sessions per GP referral and per year.

6. Make mental health support with psychologists affordable for people with ME/CFS with no or low income ie fully subsidised.
7. Make mental health support with psychologists more accessible by keeping telehealth Medicare support for all appointments with doctors and psychologists, or telehealth available with another funding model.
8. The soon to be completed Qld HealthPathway for ME/CFS will be an invaluable help, if it is taken up by psychiatrists, other mental health practitioners and the mental health sector as a whole.

I have not gone to the effort of finding references for all the points I've made as writing this letter is all I am able to do at this stage, due to reduced capacity from having ME/CFS.

Thank you for your attention. If I can be of further assistance, please don't hesitate to contact me and I'll try to help.

Please do not publish my contact details with this submission. As you hopefully will have understood, this area is contentious and difficult and I don't wish any random person to get my email or phone number off the published submissions. Thank you.

Faithfully