

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC19

Ymateb gan: | Response from: Kathryn Gower



Kathryn Gower

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I am submitting evidence as an individual

I confirm that I am over 18

I have had Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS) for 9 years this year. There are no appropriate pathways of referral to specialist services for the ME/CFS community within Wales. I, like many others are left to self manage. GP's/healthcare workers, Dr's and consultants working in hospitals either have minimal knowledge or no knowledge on ME/CFS or the symptoms. I was hospitalised in 2021, where I was at The Grange for 6 days after an adverse reaction to the Astra Zeneca. Whilst I was there, I saw a few different Dr's, nurses and consultants, and whilst I was treated well, had numerous tests quickly, and treated with respect and care, there was minimal knowledge amongst the team about what ME/CFS was, how it can affect a patient and what symptoms present. The symptoms I had in hospital were not my "usual" symptoms, so I was having to explain how ME/CFS affects me, what is "normal" and what I was experiencing wasn't "normal" for me.

It can be very hard when being admitted to hospital when you have ME/CFS because if you are not there due to ME/CFS primarily, as a patient, you are having to constantly almost teach those that are looking after you about the condition and how your symptoms are differing to those. Also, if you as a patient are admitted due to an ME/CFS flare up, or worsening of symptoms, there is a risk that how they are treating you can actually make you worse. In some cases this results in healthcare professionals getting frustrated with patients and blaming them for "not improving".

Because of the psychologisation of ME/CFS for decades, I, like the majority, have experienced gaslighting, been told to exercise more and even been told that there is nothing wrong with me. Although the 2021 NICE guidelines does stress that ME/CFS is physiological, and to not offer Graded exercise or CBT as treatments, there are still so many barriers and lack of care provision for us as patients.

One of the cardinal symptoms of ME/CFS is Post Exertional Malaise (PEM). – Which is a worsening of symptoms 24-72 hours after exertion – this can be physical, mental or emotional. This can render patients bedridden for days or weeks at a time. Most medical professionals do not understand this symptom and how severely it can affect ME/CFS patients. This means that if you are in a hospital setting, the busyness of a ward, the noise, lights, tests etc can trigger PEM in patients with those looking after them in hospital not knowing this, and when deterioration happens, they do not know how to effectively help patients. If patients are referred to physio or any kind of exercise intervention, this will make patients worse.

Overall, this can result in a lack of trust. I personally really respect the NHS and those that work tirelessly within it, however I do not trust them to effectively help or support me. As a result, I try to stay away from healthcare settings unless it is absolutely necessary, which is counter productive.

In evaluation, there is a severe lack of knowledge or attention regarding ME/CFS in Wales. In rare cases, it can be fatal– which has been largely down to medical neglect and negligence. 25% of patients are bedbound 24 hours a day, laying in darkened rooms.

Only 25% of ME/CFS patients have the ability to work. In previous studies, there is evidence to suggest that patients with ME/CFS score one of the lowest scores regarding quality of life.

Thank you for your time.

Kathryn Gower
Resident in Caerphilly.