ELCs and Experiences of Healthcare: Article 25 (Health)

In this section we discuss the difficulties faced by people with uncertain or contested medical diagnoses in accessing healthcare, and the harm sustained as a result of inappropriate treatments and institutional disbelief. We also discuss the difficulties housebound people experience accessing healthcare, and finally the impact of COVID-19 on the access to healthcare of people with energy limiting conditions (ELCs).

Medically Unexplained Symptoms, Disbelief and Harm

Disabled people with uncertain or contested medical diagnoses have unequal access to general healthcare, poorer experiences of healthcare services and often report iatrogenic harm (harm caused by medical treatment) as a result of inappropriate and unevidenced psychosomatic frameworks and treatment services. This affects many people with energy limiting conditions (ELCs). Chronic Illness Inclusion (CII) believes that this results from imbalances in the production of medical knowledge, as knowledge about disease is generated exclusively by doctors, without input from patients. This means that lived experiences of impairment and disability which do not align with existing medical knowledge about diseases are systematically invalidated.

Medically Unexplained Symptoms

ELCs are strongly associated within the UK healthcare system with the label ‘Medically Unexplained Symptoms’ (MUS). This is typically the case either because a particular condition, such as lupus, Ehlers-Danlos syndrome, or multiple sclerosis, is difficult to diagnose and thus remains ‘medically unexplained’ for years, or because the condition itself, such as ME/CFS, fibromyalgia and Long Covid, is poorly understood by medical science and labelled ‘medically unexplained’. The pathology of fatigue states in many chronic diseases is especially poorly understood.

MUS are typically taken as evidence not of genuine physical illness, but of cognitive or behavioural dysfunction,[[1]](#footnote-1) frequently resulting in psychological therapies, in particular CBT, being used to ‘treat’ MUS, in spite of the lack of evidence that this is effective.[[2]](#footnote-2) In fact, there is considerable evidence that such treatments are harmful to patients.

Evidence of harm

CII’s recent survey into women’s healthcare found that:

* A third of respondents waited more than 10 years for a diagnosis.
* Before receiving their diagnosis, four in five respondents had their physical symptoms attributed to psychosocial causes such as stress, anxiety, or being overweight, and half received psychological therapy for their undiagnosed physical symptoms, with 81% finding this therapy unhelpful and 66% finding it not at all helpful.
* Receiving psychological therapy could further diagnostic delays as all a patient’s reported symptoms were then treated as manifestations of psychological distress.
* Many respondents described the experience of having their physical symptoms attributed to psychosocial factors, which did not align with their lived experience, as ‘gaslighting’.
* Some respondents’ health deteriorated either from the exertion of attending psychological therapies, or as a direct result of interventions such as graded exercise therapy for ME/CFS or Long Covid.[[3]](#footnote-3)

This latter finding has been widely substantiated.[[4]](#footnote-4) A significant proportion of people with myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) have reported iatrogenic and treatment harms following graded exercise therapy (GET), cognitive behavioural therapy (CBT) and physiotherapy. Of a sample of 60 patients with severe ME, a third reported feeling worse after GET, a sixth felt worse after CBT and 13% felt worse after physiotherapy.[[5]](#footnote-5)

NICE reported that:

“Many people with severe ME/CFS report anger and frustration engaging with the medical profession, a significant proportion find getting a diagnosis an arduous task and are reporting that doctors have little knowledge of the illness. ... GET ranked highest for negative responses, followed by CBT and physiotherapy... Participants report that pushing beyond limits, often via participating in graded exercise therapy or physiotherapy, results in some type of negative symptom response that can last from days to months and many report associated psychological distress with such relapses.”[[6]](#footnote-6)

Patients’ beliefs and behaviours are often blamed by health care providers for the failure of CBT and other psychological therapies to improve their conditions, leaving patients with MUS feeling worse than when treatment began.[[7]](#footnote-7)

Disbelief and psychological harm

People labelled with MUS report being systematically discredited and disbelieved. In CII’s women’s healthcare survey, half of the respondents said they felt they were not listened to by health or care professionals ‘very often’, with a further 23% saying they felt this way ‘often’.[[8]](#footnote-8)

Many experience this disbelief as traumatic and are more likely to disengage from healthcare services as a result.

Respondents to CII surveys have said that:

* “With medical care I assume I will be disbelieved especially regarding ME & so keep my interactions to a minimum, this means my health care is not adequate.”
* “I am distrustful and anxious when dealing with medical professionals. It is common to be disbelieved and it puts me off seeking medical treatment in a timely fashion because I can't bear to go through all that again every time, as I find it exhausting, stressful and triggering to my PTSD. At times I have been treated like a liar and a malingerer purely because I am well educated in my conditions.”
* “I don’t trust health and care providers. My health - both mental and physical - have deteriorated and I have refused to seek help.”
* “I don't trust medical people any more. I try to be optimistic and friendly (or at least to seem to be), but every time I need to see or speak to a GP, I get really nervous and depressed because the normal scenario is that I have asked for help in vain.”
* “I do not believe my GP has my best interests at heart. As a result of how I am treated I do not trust my doctors.”
* “I hate speaking to the doctor now, I'm always nervous before I call. I expect not to be believed or listened to.”
* “Now when I have concerning symptoms, I don't know if I should seek medical care as I don't know if I'll be believed. So I don't listen to my body or see doctors, even when I have new and significant chest pain, for example. So I am concerned that as I get older, I might end up seriously ill or dead because I've been taught that my symptoms will not be taken seriously when I see a doctor.”
* “I have been traumatised by medical gaslighting to the extent that I [am] frightened to go to the doctor now. When I do go, it takes me days to recover. I have anxiety attacks and become suicidal.”

This disbelief can have a detrimental impact of people’s self-esteem and psychological wellbeing. Respondents to CII surveys have also said that:

* “I feel like it makes me less valid as a person as people see me as dishonest and a liar even though it's not me. I don't feel I can be fully open about my conditions [and] health care professionals see me and think I'm making it up even though I know I'm not, and so I feel like I'm never fully myself and this effects my self esteem as I don't feel like I can just be me and the other people can understand who I am. [I] feel like less of a person.
* “I have developed anxiety about being believed & taken seriously especially with professionals, I struggle with a sense that I am seen as worthless by society in general. I have become apologetic & unassertive.”
* “When you are constantly disbelieved you start to query yourself and over long period of times this wears you down.”
* “Am I making this up? Is it not that bad? I don’t deserve care since it’s being withheld.”
* “Being treated as untrustworthy and an unreliable witness to one's own experiences is damaging. Being called a hypochondriac, treated as a time waster, or considered unworthy of help makes one feel worthless.”
* “I don't believe myself any anymore. I can't trust myself and I'm constantly questioning. I feel worthless. It's like a mantra in my head now: "Who are you? No one. What are you? Nothing. You are nothing. Shut up." Stop whinging. Stop focusing on yourself. Stop thinking about yourself. Who are you? No-one. What are you? Nothing. Shut up.”

This experience of disbelief is deeply gendered, with women being at a much greater risk of medical disbelief than men. Additionally, most of the conditions labelled ‘medically unexplained’ are more often experienced by women than men, and the lack of knowledge about them stems from a gendered imbalance in biomedical investigations, where women’s illnesses are vastly under-researched.[[9]](#footnote-9) This should be a particular concern for the committee, given the commitment in Article 6 to recognising the multiple discrimination against women and girls.

It is very difficult for patients to address this gap in medical knowledge because of the imbalance of power between them and their doctors: doctors are regarded as the experts and patients’ opinions or experiences of their own bodies are less valid. Where there is a disagreement between the two, doctors are always presumed to be in the right.

No mechanism for reporting harms to MUS patients

This pattern of medical neglect has become pervasive in part because UK agencies tasked with monitoring harms to patients, such as the Yellow Card scheme operated by The Medicines and Healthcare products Regulatory Agency (MHRA), and the new proposed Patient Safety Commissioner and Redress Agency, only look at harms from “medicines and medical devices”,[[10]](#footnote-10) and do not consider potential harms to patients from psychosocial and behavioural interventions.

MUS framework as a healthcare spending reduction strategy

Patients with MUS are often made to feel like a drain on NHS resources, such as one focus group participant who said that they had been called “a burden on NHS care”.

There is evidence that this is how the NHS itself views MUS patients. The IAPT manual for treating MUS with CBT explains:“chronic repeat attenders account for 45% of primary care consultations and 8% of all emergency department attendances; the most common cause of frequent attendance is an untreated mental health problem or MUS”.[[11]](#footnote-11) This treats the frequent attendance of these patients as the problem, rather than the patients’ poor health.

It appears that part of the motivation for ‘treating’ MUS with psychological therapies may be to reduce spending. NHS England states that the strategy of including MUS under the IAPT programme “is more cost effective and can reduce a person’s use of physical health services: this can reduce the annual expenditure per person by £1,760,”[[12]](#footnote-12) and that it should “address problematic beliefs and behaviours that may increase the impact of LTCs [long term conditions] on people and their families and carers”.[[13]](#footnote-13)

Recommendations

* Knowledge production in medical science and healthcare must involve and engage patients and the public, not only to ensure co-production of knowledge, but also to avoid top-down hierarchical service provision and iatrogenic harm.
* More biomedical research should be carried out into conditions that predominantly affect women. Spending on MUS services under IAPT must be redirected to investment in biomedical research on ELCs.
* Healthcare professionals should receive extensive training on the (often unconscious) impact of gender biases on the credibility afforded to a patient’s report of their symptoms.
* The MUS concept can no longer be accepted as a viable diagnostic term.Use of MUS as a quasi-diagnostic category should be stopped because it obstructs access to needed medical diagnosis and care. Every time a doctor uses an MUS label to explain physical symptoms as psychosomatic, a patient in need of medical care may be denied access to it.
* A mechanism for reporting harm from cognitive behavioural treatments must be implemented. It is vital that the safety and effectiveness (or lack of effectiveness) of psychological and behavioural interventions is also covered by the Yellow Card scheme and a future Patient Safety Commissioner and Redress Agency. This agency must also be prepared to look hard at the potential for conflicts of interest in those conducting any such research.
* Any commitment to listen to patients and protect them from harm must extend to behavioural and psychological treatments. The merit and safety of these interventions is often backed up by poor science which escapes the greater scrutiny given to research on drugs and medical devices.

Access to healthcare for housebound people

People who are frequently unable to leave their homes because of ELCs, which fluctuate unpredictably, can struggle to access healthcare, including not only doctors’ appointments, but also health prevention and screening services.

In a recent survey by CII, only 12% of respondents had ever received a home visit by their GP, fewer than 2% had ever received a domiciliary or sexual health screening service, and only 5% had accessed domiciliary dental care. Respondents were often refused not only home visits but even telephone appointments, and many were unaware that they could request domiciliary services as a reasonable adjustment. Many felt too afraid, ashamed, or hopeless to request domiciliary services, and many were denied such services because their testimony about the impact of their symptoms was not believed by service providers. One respondent had “gone without treatment for weeks or months until I have a period of improved symptoms and can go out to get care”.[[14]](#footnote-14)

Please see Part II of this submission for a note about CII’s use of the term ‘housebound’.

Access to healthcare and COVID-19

The COVID-19 pandemic has had a detrimental impact on people’s access to healthcare. Nearly 6 million people in England, which amounts to 9% of the population, are currently waiting for surgery.[[15]](#footnote-15) 42,430 patients were waiting more than two weeks to see a cancer specialist after being urgently referred by a GP in October, the highest figure in 12 years, and only 67.8% of cancer patients received their first treatment within two months of urgent referral.[[16]](#footnote-16) In October the average ambulance response time was 53 minutes and 54 seconds, three times the target of 18 minutes.[[17]](#footnote-17) 121,000 people waited at least four hours for A&E services, with 7,059 people waiting more than 12 hours.[[18]](#footnote-18) The Royal College of Emergency Medicine estimated that over 6,000 patients were dying every year because of the overcrowding of A&E.[[19]](#footnote-19) A record 5.8 million patients were waiting to start routine hospital treatment at the end of September 2021.[[20]](#footnote-20)

People with ELCs have been badly affected by these delays to accessing healthcare. In a recent CII survey, 66% of respondents under the regular care of a GP or specialist reported disrupted access to care since the pandemic began, and 56% reported a decline in their health.[[21]](#footnote-21) Responses to this survey regarding access to healthcare have been outlined in Part III of this submission.

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