DISBELIEF AND DISREGARD: GENDERED EXPERIENCES OF HEALTHCARE FOR PEOPLE WITH ENERGY LIMITING CONDITIONS

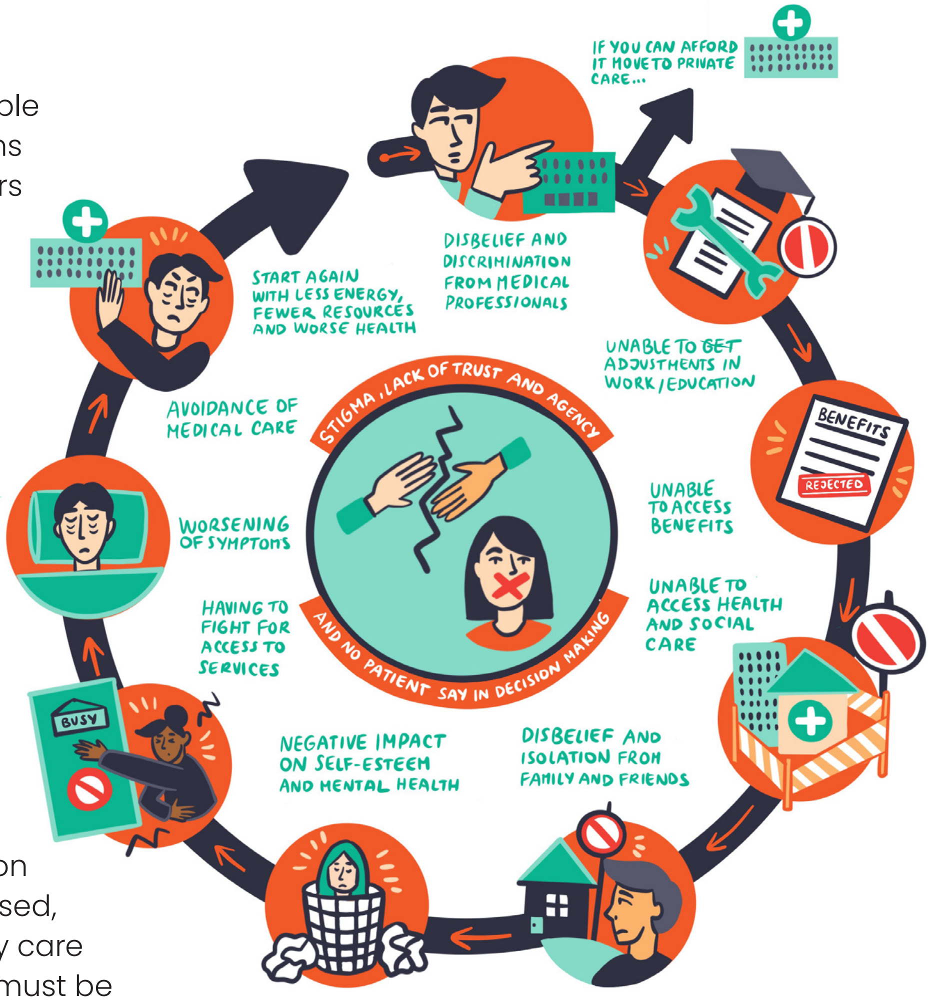
"FOR OVER TWENTY YEARS, NO-ONE BELIEVED I HAD A PHYSICAL HEALTH CONDITION"

BRIEF
3

CHALLENGES OF DELAYED OR MISDIAGNOSIS

Introduction

Our research shows that people with Energy Limiting Conditions (ELC) experience many barriers when accessing healthcare and these barriers create health inequalities. The data suggest that poor access to healthcare and poor continuity of care has a direct and detrimental impact on chronic illness. Chronic conditions challenge models of healthcare that focus on cure, as for many of these conditions a cure is not currently available. In the absence of a cure, people need reliable access to healthcare based on providing good, evidence-based, continuous care from primary care and specialists. This process must be based on the needs of the patient.



Pathway to Inequality

Our research findings show that a healthcare system that does not respond to the needs of people with chronic conditions exacerbates those conditions and generates forms of health inequality that deserve much greater attention. In this brief we focus in particular on challenges associated with delays and difficulties in getting an accurate diagnosis. For more information on the background and methodology used in this research, see brief 1.

Disbelief and Difficulty in Obtaining Diagnosis

One of the key health inequalities experienced by people with ELC relates to how difficult it can be to obtain a diagnosis in the first place. For 31% of participants, it took more than ten years to obtain a diagnosis. This raises serious questions about the failure of our current healthcare system to meet the needs of these people. Whilst some conditions may not have clear diagnostic tests, it is clear in our data that a key barrier to quick diagnosis was the disbelief healthcare that patients with ELC encountered from professionals throughout the system.

Of 816 people who answered the question, 75% said that they often or very often felt that they were not listened to by health or care professionals and 64% of 813 people who answered the question said that they often or very often felt that their account of how their condition affects them and impacts their life was not believed by a health or care professional. One woman recalled her twenty-year struggle to be taken seriously when she sought an explanation for her fatigue and joint pain:

"I first started complaining of joint pain and fatigue before I was 8; that's how old I was when my parents took me to the doctor about it the first time. For over twenty years, no-one believed I had a physical health condition. GPs, consultants, nurses, physios, OTs all wrote it off as growing pains, avoiding school, avoiding PE, and as I got into puberty it became attention seeking, depression, all in your head, acting out. It was even worse as I had (then undiagnosed) autism and severe depression and anxiety. I got told so often that I wasn't in pain that I still sometimes can't understand why I feel bad until someone asks, specifically, 'does your ____ hurt?' I was 28 before I found out that the normal amount of pain most of the time is zero, none at all. I don't remember ever not being in pain. The diagnosis of Ehlers Danlos in my late twenties made sense of so much of my past, but by then all the time I'd spent pushing through and ignoring my body because it was 'all in my head' and 'you can't have hurt yourself badly just from that' had physically wrecked my body, permanently. No-one believed me, not one person ever stopped to wonder why - how! - an eight-year-old would be faking joint problems." Participant 644: age 35-44, white, bisexual, woman, England.

In many cases, a person's health deteriorates further while they are caught in a cycle of seeking and being denied medical care. Intersecting forms of oppression combine here with additional barriers to adequate health care in the form of racism, ageism, homophobia, transphobia, ableism and fatphobia (for more information, see brief 5). Class or income also matters, as paying for private consultations was, for some participants who could afford it, a route to being listened to:

"Every health condition I have, I was not listened to at first. In many cases I had to pay for private assessments in order to get the NHS to listen to me. Because my income is very low, I have still not had proper assessment of some of my conditions and I have been unwell for over 20 years." Participant 884: age 35-44, white, bisexual, non-binary, England.

The worse someone's symptoms become, the more likely they are to need specialist treatment in the future, and so the failure to believe and support people at the primary care level not only generates greater health inequalities, it also increases pressure on the provision of tertiary care. Difficulties with diagnosis also influence other areas of people's lives. For instance, without a medical diagnosis it is very difficult to obtain access to benefits or to obtain reasonable adjustments in employment, both of which have significant implications for a person's quality of life (for more information, see brief 4). This also exacerbates income inequalities as a lack of reasonable adjustments or access to benefits leaves people without other financial resources in dire circumstances (notably, these data were collected before the current cost of living crisis):

"I have been homeless multiple times but unlike other disabled people I have still not been able to get a council property even though I see myself as hugely disadvantaged in being able to afford a home in the private sector when I can't manage more than 25 hours work a week or else I will bring about more relapses." Participant 519: age 45-54, white, heterosexual, woman, England.

"[I] had my PIP [Personal Independence Payments[1]] taken away and had to fight a tribunal and get My MP involved as I couldn't work and couldn't afford my bills or food." Participant 45: age 45-54, white, heterosexual, woman, England.

Symptoms Diagnosed as Mental Health Conditions

As well as feeling regularly disbelieved or dismissed by healthcare professionals, many of our participants shared experiences of their symptoms being attributed to mental health conditions. The examples shared with us show that this not only happens in situations where the cause of symptoms may be unknown but also in cases where a very clear explanation could easily be found if the correct investigations were carried out. This situation can create unnecessary further suffering and the provision of unsuitable, in some cases harmful, treatment strategies. Whilst some people may have both ELCs and mental health conditions, and living with a chronic illness can cause poor mental health, our participants' experiences suggest that a mental health diagnosis has become a "catch-all" diagnosis when doctors do not know the correct investigations to carry out, want to dismiss the complaint, or do not want to allocate further resources for investigation. Some participants understood this to be influenced by sexist histories and approaches within medicine, such as attributing women's symptoms to hysteria. For example:

"Because I'm a young female everything is put down to anxiety because I'm not medically easy to deal with. I'm constantly gaslit and have my physical symptoms belittled because I'm really annoyed with the situation of not having a diagnosis.... therefore, I'm a hysterical female." Participant 697: age 18-24, white, woman, England.

Participants told us about the detrimental impact of being misdiagnosed with mental health conditions:

"Unusual physical symptoms were routinely treated as somatic disorders. The original diagnosis of depression and anxiety when I was 30 has cast a very long and unhelpful shadow across all the rest of my healthcare since, to the point that I largely disengaged with the healthcare system. This was to my detriment." Participant 750: age 65+, white, heterosexual, woman, Scotland.

"Due to the excessive fatigue from Long Covid, my GP would consistently say my symptoms were due to mental health, anxiety or depression." Participant 536: age 25-34, white, heterosexual, woman, England.

Diagnostic Overshadowing

Many participants told us that once given a diagnosis, they found it extremely difficult to get other possible illnesses or co-morbidities investigated properly as health professionals tend to attribute everything to the original diagnosis. In some cases, this "diagnostic overshadowing" leads to people avoiding medical professionals until absolutely necessary (for further information see brief 2):

"It took me three separate doctor's appointments over three weeks for them to take my abdominal pain seriously. Turned out it was related to my coil and not my fibromyalgia as I had been repeatedly told and dismissed because of it." Participant 103, age 25-34, white, pansexual, woman, England.

"In general, once I got a diagnosis for ME/CFS, it then became the 'default' reason [for] GPs for any other health issue that came up. It's like, 'you have ME, that's all you are and there is no treatment, go away, we aren't interested in helping you now'. So peri-menopausal issues are ignored [because] I have ME." Participant 324: age 45-54, white, non-binary, England.

Diagnostic overshadowing was also experienced by participants in the form of weight stigma or fatphobia. 15% of participants who answered the corresponding question said that prior to their current diagnosis their symptoms had been attributed to being overweight, obese, too fat, needing to lose weight, overeating, lack of will power, or lifestyle factors related to weight. This rises to 65% of respondents who have lipoedema, a condition characterised by the abnormal build-up of fat (for further information see brief 5).

Recommendations

Listening and believing

The medical profession must take seriously the harms done to the health and wellbeing of people living with energy limiting conditions. This begins with listening to and believing patients, learning from and responding to lived experiences of ELC with respectful and effective care.

Better care

Healthcare for people living with ELC must improve. Better patient pathways and quality of care are needed for people with ELC. This includes the provision of appropriate treatment or symptom management, continuity of care and timely referral to multi-disciplinary and specialist services. In all of this, trust and shared decision making between patients and professionals is vital.

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[1] Underlined text indicates a hyperlink. If reading this on paper, see table at end of brief for web addresses.

Training

Training of all health, social care, and welfare professionals must include information about energy limiting conditions, based on up-to-date research and the lived experiences of patients. This must extend to continuing professional education.

Tackling discrimination

Institutional sexism continues to play a part in the poor quality of care many women with ELC face. Tackling institutional sexism in health, social care and welfare systems is essential but is also not enough. Intersecting forms of oppression, including racism, ageism, homophobia, ableism, transphobia and fatphobia must also be eradicated. More research is needed into the intersectional nature of experiences of energy limiting conditions. Such research needs to inform the development of more inclusive services in healthcare that are grounded in respect, belief and addressing intersectional marginalisation.

Reforming support systems

People with ELC need support in accessing welfare, social care, employment and education. Complicated, hostile and exhausting systems are significant barriers for those without the energy to fight the system. Simpler and more supportive processes are vital. In instances where the healthcare and welfare systems have been unresponsive to the needs of patients, or where harm or neglect has been experienced, people with ELC must be better supported when making complaints and appeals, and in accessing advocacy. The onus should not be placed entirely on patients to navigate a system that has already proven to be hostile to them; nor should the burden of proof be with patients.

Inclusion in research and policy decisions

People with ELC must be part of conversations about policy and practice that affects them, and equal partners in research on ELC. The accessibility of patient and public involvement frameworks must be improved to ensure the inclusion of people with ELC. This might, for example, include asynchronous and remote modes of participation. (see brief 6 for further recommendations on including people with ELC in research).

Pathway to Equality

Page	Linked text	Hyperlink
3:3	Personal Independence Payments	**https://www.gov.uk/pip**

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Project website: http://disbeliefdisregard.uk/ *Illustrations*: Nifty Fox Creative
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