

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

# “DISBELIEF MADE ME FEEL WORTHLESS”

BRIEF  
**2**

## THE IMPACT OF POOR HEALTHCARE ON MENTAL HEALTH AND WELLBEING

### Introduction

Our research shows that poor healthcare has a harmful impact on the mental health and wider wellbeing of people with Energy Limiting Conditions (ELC). This brief highlights the psychological harms experienced by our participants as a result of poor healthcare in relation to: medical sexism and intersecting forms of discrimination; the damaging impact on mental health of disbelief and disregard within health and social care systems; disbelief from medical professionals leading to avoidance of healthcare; and the impact of disbelief on relationships with friends and family. For more information on the background and methodology used in this research, see brief 1.



### Medical Sexism and Intersecting Forms of Discrimination

Our healthcare systems are still influenced by the [patriarchal structures and attitudes](#)<sup>1</sup> that have long informed medical practice. Many participants felt that the poor healthcare they experienced was explicitly gendered and often reflected harmful stereotypes. During interactions with healthcare professionals, participants often felt patronised, infantilised and/or dismissed due to their gender. Participants told us that their health concerns were often dismissed as “normal” for women, and therefore they were expected to manage their symptoms independently. One participant said:

**“My symptoms have often been dismissed as ‘just normal’ for being a woman... it’s OK when a woman suffers because that’s what they do and that’s their lot.”** Participant 198: age 45–54, white, asexual, woman, England.

<sup>1</sup> Underlined text indicates a hyperlink. If reading this on paper, see table at end of brief for web addresses.

Other participants shared experiences of dismissive and misogynist/sexist attitudes to women's pain during consultations:

**"One doctor said I should expect to be in pain because it was 'common for women of my age'. I was 38."**

Participant 971: age 45–54, white, heterosexual, woman, Scotland.

**"[A] pain specialist told me that the reason I 'wasn't coping' (I was coping fine) was because women are weaker and can't handle pain as well as men."** Participant 46: age 45–54, white, bisexual, woman, England.

Participants told us their healthcare was often reductionist, with a focus solely on reproductive health. For example, one participant said:

**"[The] majority seem to put any condition [down to] either puberty, PMT, menopause, [or] periods."**

Participant 624: age 55–64, white, heterosexual, woman, Wales.

**"I was speaking to my GP about fibromyalgia management, figuring out treatment plans as the current regimen wasn't working sufficiently. He told me that I should get pregnant as 'that would sort me right out', gesturing vaguely at my body."** Participant 737: age 25–34, white, straight/queer, woman, England.

Some participants found they were taken more seriously when they took a man with them to consultations:

**"I have learned to spot when I'm not being believed and now ask my husband (who has a PhD so can call himself 'Dr') to speak on my behalf. Things which I'm told are impossible, are immediately fine when he asks for them."** Participant 771: age 35–44, white, heterosexual, woman, England.

Requiring a male advocate erases the dignity of self-advocacy and reinforces psychological harm:

**"My confidence is at an all-time low after several poor GP consultations in one year. I was made to feel like a problematic 'at that age' female. In the end I would take my husband for support and so I was taken seriously."** Participant 608: age 45–54, white, heterosexual, woman, England.

Participants also explained that they saw the gendered assumptions they encountered in healthcare as being part of a broader and historical pattern of medical sexism or misogyny:

**"I think there is a long legacy of medical misogyny, and conditions affecting women are discounted and attributed to psychological factors, rather than taken seriously and researched."** Participant 381: age 55–64 white, heterosexual, woman, England.

This discrimination is exacerbated for people who experience multiple intersecting forms of oppression. As one participant explained:

**"So much more needs to be done especially for women of colour who are referred to in derogatory ways."**

Participant 65: age 35–44, British Asian, heterosexual, woman, England.

This participant linked to [an article about the use of racist terms "Begum syndrome or Bibi-itis"](#) to dismiss the legitimacy of South Asian women in medical encounters.

For younger people with ELC, ageism often means their experiences are dismissed as "puberty or growing pains" and for people of menopausal age, symptoms are often not fully investigated but attributed to menopause.

For LGBTQIA+ people with ELC, medical misogyny is further exacerbated by homophobia and/or transphobia. Participants reported:

**"With bladder problems caused by surgical complications, doctors attributed this to 'lesbianism', 'poor hygiene' and other things, for some years, before admitting the problem."** Participant 887: age 35–44, white, lesbian/gay woman, England.

**"I also have been repeatedly ignored when I explain that I can't be pregnant as I haven't had sex with anyone other than my cis girlfriend."** Participant 548: age 18–24, white, bisexual, woman, England.

For transgender participants, transphobia also affected their access to adequate healthcare. As one participant explained:

**"Merely being trans means I have been refused treatment by multiple GPs in the past, so I don't dare to ask. I just make sure I am accompanied by a witness to appointments."** Participant 887: age 35–44, white, lesbian/gay woman, England.

Fatphobia or weight stigma also shaped the way in which medical sexism impacted participants' experiences of healthcare. Diagnostic overshadowing meant that symptoms weren't investigated, but attributed to participants' weight with instructions to "stop being lazy," and lose weight. For more information on diagnostic overshadowing, see brief 3 and for more on intersecting forms of oppression, see brief 5.

## Disbelief and Disregard Damage People's Mental Health

Participants clearly stated that poor healthcare, and specifically disbelief and disregard, have damaged their self-esteem and self-confidence. Experiences of "medical gaslighting" left participants feeling traumatised, distressed, and depressed. Participants explained how being disbelieved when they sought medical help made them question their "value", core beliefs and self-knowledge:

**"It knocked my self-confidence, and self-belief that I know my body. It made me start to doubt myself."**

Participant 441: age 45-54, white, heterosexual, woman, England.

**"I have been made to feel like a liar, disrespected, unbelieved, humiliated, judged, worthless, a scrounger and suicidal."** Participant 429: age 45-54, white, heterosexual, woman, England.

For many, being disbelieved and disregarded was not a one-off isolated event, but something that happened on multiple occasions in multiple settings. As a result, for many the psychological impact of not being believed was cumulative and long term. One participant explained that:

**"When you are constantly disbelieved you start to query yourself and over long periods of time this wears you down."** Participant 21: age 65+, white, heterosexual, woman, England.

Other participants talked about feelings such as guilt, feeling unimportant and feeling they were somehow undeserving of care:

**"[Disbelief] makes you feel exhausted, but also guilty - you are made to feel like you're wasting someone's time or you're being uppity by challenging a doctor. I was told recently that 'You must get the idea that you have endometriosis out of your head' by a gynaecology consultant (contrary to the opinions of 3 GPs and 3 other gynaecologists I had seen) and had to make a formal complaint - the whole experience left me feeling angry but also irrationally guilty."** Participant 547: age 18-24, white, bisexual, woman, England.

**"[You] feel your life is not important. That you are complaining about nothing. [You] feel nobody cares that you are suffering. You feel unimportant, worthless."** Participant 577: age 55-64, white, heterosexual, woman, England.

For many participants, this continued disbelief and disregard lead them to question their own lived experiences and, in some cases their own "sanity". These experiences were particularly evident for people with fluctuating conditions.

**"Am I making this up? Is it not that bad? I don't deserve care since it's being withheld."** Participant 697: age 18-24, white, woman, England.

**"Being disbelieved has caused such distress, I have questioned my sanity and constantly gaslit myself. I've thought I must be wrong or somehow bad."** Participant 754: age 25-34, white, bisexual, gender fluid, England.

**"Feeling as though I'm making things up because my condition varies; doubting my own lived experiences because of that."** Participant 81: age 25-34, white, lesbian/gay woman, England.

One participant summarised the psychological damage that medical disbelief can cause:

**"I believe it greatly contributed to the deterioration of my mental health. It made me feel invisible, worthless, it shattered my world view. You might be treated badly by individuals in the wider world, but this was supposed to be a place of professionalism, the caring profession."** Participant 110: age 65+, white, heterosexual, woman, England.

## Disbelief and Avoidance of Medical Care

Being disbelieved erodes the trust that patients have in healthcare professionals, with consequences for worsening health and the generation of greater inequalities. Our participants told us that when disbelief and disregard become routine experiences, they become reluctant to seek help and they begin to avoid medical encounters as much as possible.

Participants talked about feeling traumatised by past experiences of disbelief and gaslighting by healthcare professionals:

**"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."** Participant 884: age 35-44, white, bisexual, non-binary, England.



**“I am anxious about every single medical interaction, even when the doctor or whoever turns out to be good. It not only makes me fearful but it makes me present in a manner which is not me. I am reluctant to seek help for problems and try to deal with things myself. I prefer to stay invisible to them as much as possible but I need medication and support for benefits.”** Participant 434: age 45–54, white, bisexual, woman, England.

Participants know that not seeking help risks harming their health, but many told us that they chose pain and physical discomfort over the harm of a medical encounter in which they are disbelieved and disrespected:



**“I stay away from health providers as much as possible and have on occasion become very unwell by avoiding or delaying asking for help. My health records now do not reflect the true state of my health, as in general I do not bother to report problems anymore.”** Participant 318: age 55–64, white, heterosexual, woman, England.

**“I avoid going to [the] GP when I should for serious things. For example, I have bad vaginal pain at the moment, but I feel I just get looked at like a hypochondriac.”** Participant 856: age 35–44, white, heterosexual, woman, England.

**“I am deeply traumatised longterm from protracted mistreatments, abuse and interrogations by health and care providers. I suffer very poor physical and mental health as a result. I am no longer able to access any care support as the trauma has left me so disturbed that I can no longer undergo assessments to access any support.”** Participant 844: age 55–64, white, woman, England.

Intersectional forms of oppression matter here too. One participant explained that due to racism as well as sexism, they would rather:

**“Just ride out the pain and any other symptoms than to try again for a medical diagnosis and relevant treatment.”** Participant 400: age 25–34, mixed-race, bisexual, woman, Scotland.

Positive experiences with medical professionals can go some way towards rebuilding this lost trust in the medical profession, but it can take time:

**“It took many years, and finding a doctor in my local surgery who had seen the pain I was in, and who believed me, to get me an appointment with a specialist, before I learned to trust the medical profession. Still not totally, but better than it had got to.”** Participant 9: age 55–64, white, heterosexual, woman, Wales.

**“After many years of poor responses, I cried when a new GP listened and confirmed what I knew/experienced. It was validation. Prior to this, experiences [had] been very poor, leading me to become angry, defensive and to lose any faith in the service.”** Participant 953, age 45–54, white, heterosexual, woman, England.

## Impact of Disbelief on Relationships with Friends and Family

In addition to the breakdown in relationships with healthcare professionals, participants also explained how the disbelief of healthcare professionals, amplified through the media, has a negative impact on relationships with friends and family (see brief 4 for the impact on relationships with employers). This participant's experience was echoed by many others:

**“Not being believed by someone who is medically trained makes you wonder ... how my friends and family [can] understand if the health professionals don't seem to. It's certainly impacted my mental health. I feel very vulnerable around people now, have felt disbelieved and not listened to. I find I get very defensive or disheartened by this, and often [feel] quite alone.”** Participant 64: age 25–34, white, heterosexual, woman, England.

The powerful social position of healthcare professionals, particularly doctors, and the fact that people are conditioned to view them as experts, often means that patients' families and friends hold medical opinion in higher esteem than their relative/friend's lived experience:

**“Because healthcare professionals dismiss and neglect me, my family question how serious my conditions are and practically accuse me of malingering/exaggerating. They always say, ‘If it was that bad they wouldn't leave you like this’. I get no support from friends or family and my husband and I are left to manage and suffer alone. My poor husband is 61 and ill himself, so this is awful.”** Participant 302: age 45–54, white, heterosexual, woman, England.

Dismissal by healthcare professionals can also make people in abusive relationships even more vulnerable:

**“It was incredibly dangerous when I was in an abusive relationship. The disbelief of medical professionals allowed him even further control over me, resulting in worsening of abuse and control, and further putting my children at risk.”** Participant 827: age 35–44, white, bisexual, non-binary, England.

## 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, and 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.

### Training

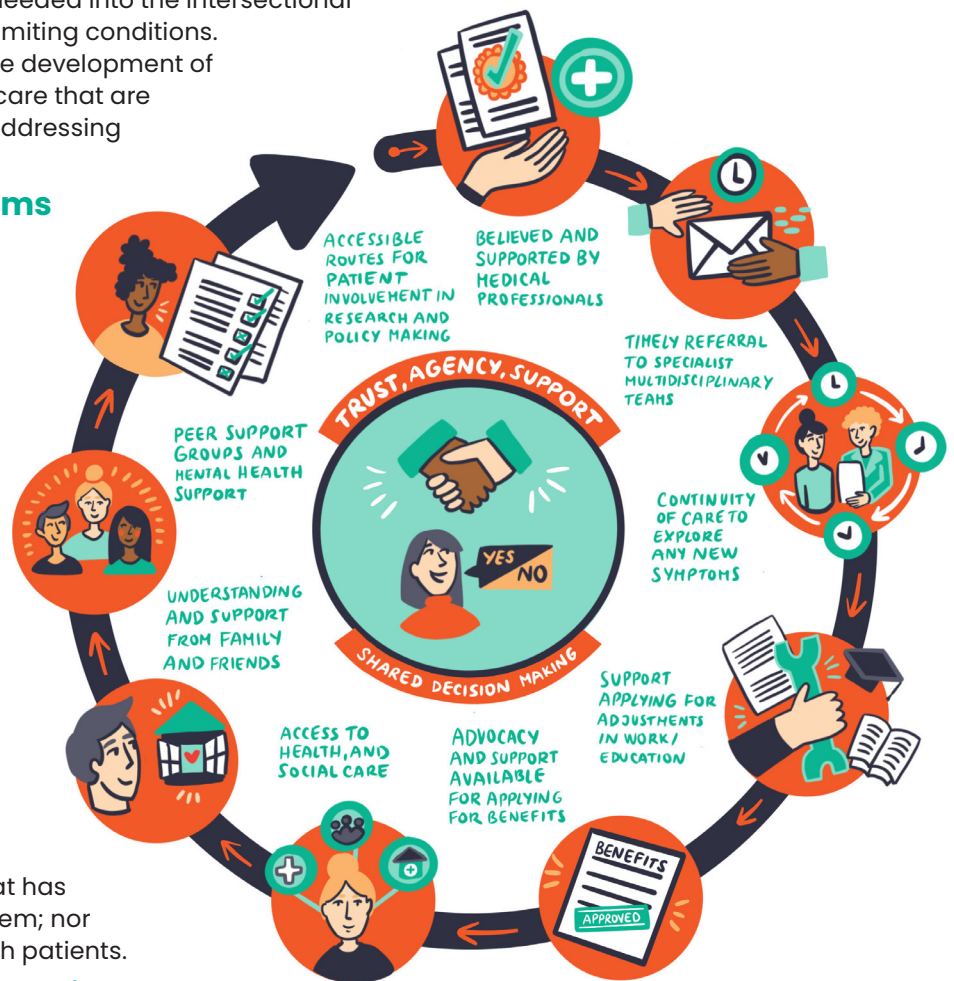
Training of all health, social care, and welfare professionals must include information about energy limiting conditions, based on up-to-date research and the lived experiences of patients. This must extend to continuing professional education.

### 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

<b>Page</b>	<b>Linked text</b>	<b>Hyperlink</b>
2:1	"patriarchal structures and attitudes"	<a href="https://www.newscientist.com/article/mg25033400-100-the-gender-pain-gap-has-gone-on-for-too-long-its-time-we-closed-it/">https://www.newscientist.com/article/mg25033400-100-the-gender-pain-gap-has-gone-on-for-too-long-its-time-we-closed-it/</a>
2:2	"an article about the use of racist terms "Begum syndrome or Bibi-itis""	<a href="https://www.bmj.com/content/368/bmj.m535/rr">https://www.bmj.com/content/368/bmj.m535/rr</a>