

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

**“INTERSECTING IDENTITIES MAKE IT MORE COMPLEX TO ACCESS SERVICES AND HEALTHCARE”**

BRIEF  
**5**

**THE INTERSECTION OF SEXISM AND OTHER AXES OF OPPRESSION**

### Introduction

Sexist approaches to Energy Limiting Conditions (ELC) influenced the disbelief and disregard encountered by our participants in multiple ways. These experiences are exacerbated or tempered by other forms of oppression and privilege which intersect with sexism, including racism, ageism, homophobia, transphobia, fatphobia and ableism. As one participant explained:

**“I think that attention also needs to be paid to women and non-binary people who have intersecting identities that make it even more complex to access services and healthcare. I’m older, LGBT, gender queer, Disabled”.** Participant 915: age 55–64, white, lesbian/gay, gender queer, England.

In this brief we outline the experiences of disbelief and disregard in relation to these intersecting forms of oppression. For more information on the background and methodology used in this research, see brief 1.



## Race and Ethnicity

While the limited diversity of our participants precludes detailed quantitative analysis, a higher percentage of participants (81%) who identified as mixed race (n=31) said that they often or very often experienced not being listened to by healthcare professionals than the percentage for all participants (75%). As one participant suggested:

**“I want all HCPs [Health Care Professionals] to address their racial bias and misogyny.”** Participant 541: age 25–34, mixed-race, queer, woman, England.

Some participants explained that their experience of racism in medical encounters also intersected with ableism, and this made it difficult for them to access adequate healthcare:

**“I feel as a Black [person] with possible autism getting the right healthcare has been difficult”.** Participant 878: age 55–64, Black, bisexual, woman, England.

**“BME [Black and Minority Ethnic] women face so much institutional racism and disablism, barriers and inequalities.”** Participant 932: age 55–64, British Asian, heterosexual, woman, England.

As one participant explained, there is an urgent need to address institutionalised forms of racism and sexism:

**“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 backed this up with a link to a [BMJ article](#) about the use of racist terms **“Begum syndrome or Bibi-itis”** to dismiss the legitimacy of South Asian women. Participant 65 continued, explaining that: **“Women of colour often also carry colonial traumas and physical traumas e.g. energy impairment, and the lack of belief services and understanding in the system just perpetuates those traumas.”**

As a result of the combination of racism and sexism in the healthcare system, some participants explained that they now avoid seeking help:

**“It is a tiring process trying to receive comprehensive medical care and sometimes I think I’d rather just ride out the pain and any other symptoms than to try again for a medical diagnosis and relevant treatment. In addition to racism, sexism is an issue, and I have experienced [it] from the medical consultants I tried to discuss my symptoms with. They have not been particularly helpful, not been interested in finding different, less invasive options, and they can be dismissive and lack bedside manner.”** Participant 400: age 25–34, mixed race, bisexual, woman, Scotland.

Participant 400 went on to explain that they felt there wasn’t enough interest from medical professionals in **“learning or expanding their knowledge beyond their white perspective- based textbooks”.**

## Age

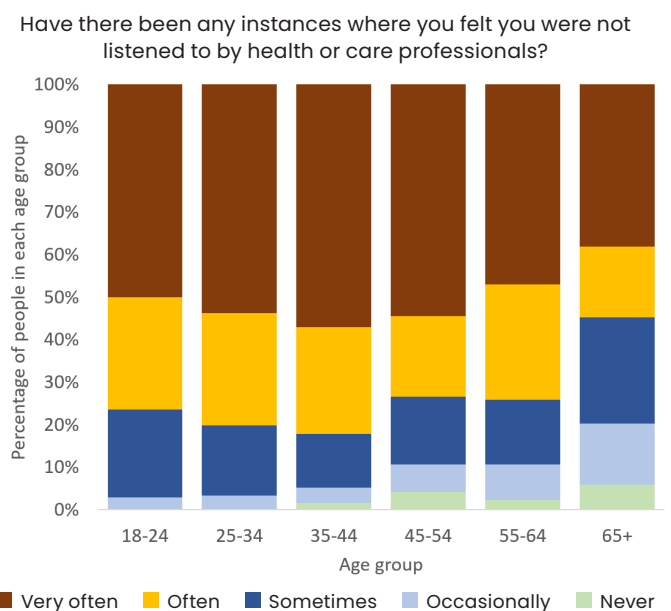
The percentage of participants reporting that they “often or very often” felt that they weren’t listened to or believed by healthcare professionals was highest in the lower three age ranges, and lowest in the highest age category.

In the qualitative data, many participants now in older age categories said that they had faced disbelief when they were younger. Multiple participants reported having their symptoms dismissed as “growing pains”, “puberty”, “just being a teenager” or that they were told they were too young to be experiencing the symptoms they reported:

**“The first GP I saw with ME symptoms told me it was my age and the symptoms would go eventually.”** Participant 370: age 55–64, white, heterosexual, woman, England.

**“I was told I was too young to suffer this, so my concerns & symptoms were irrelevant.”** Participant 714: age 45–54, white, heterosexual, woman, England.

Further age-based forms of exclusion were evident in participants’ experiences of being denied access to mobility aids and domiciliary and social services support because they were “too young”:



**“My GP does not provide home visits to anyone not elderly. It’s [go to] them, no help, or an ambulance.”**

Participant 728: age 45–54, white, heterosexual, woman, England.

**“Social services is not set up to support a younger person who wants independence.”** Participant 829: age 25–34, white, bisexual, woman, England.

That’s not to say that older women didn’t face challenges in getting appropriate care:

**“Women my age seem to be forgotten about, I am 70 years young.”** Participant 152: age 65+, white, heterosexual, woman, England.

**“As far as my GP surgery is concerned, I am now an old woman of no importance and have to fight them at the time when I actually need their help most.”** Participant 158: age 65+, ‘other ethnic group’, heterosexual, woman, England.

Participants of menopausal age reported diagnostic overshadowing as their symptoms were often attributed to menopause or pre-menopause with no further investigation. In some cases, participants were inappropriately prescribed HRT:

**“[There is an] assumption that pre-menopausal symptoms explain presented issues or that everyone knows what those are. For example, I have had several references to my age by medical staff: ‘well, you are 50!’ Only later have I understood this was an implied reference to menopausal symptoms and not my general physical capacity when explaining away my concerns about pain, fatigue or mental impairment.”** Participant 357: age 55–64, woman, England.

## LGBTQIA+ People

Participants who identified as LGBTQIA+ had worse experiences than those who identified as heterosexual or cisgendered. Across all participants 75% reported often or very often feeling they weren’t listened to by healthcare professionals, but this number rises to 85% for LGBTQIA+ participants. The qualitative data identified a range of problems and forms of discrimination that LGBTQIA+ people with ELC faced in seeking appropriate healthcare.

Participants reported experiencing healthcare spaces as heteronormative, where the assumption was that people were heterosexual or cisgendered until they disclosed otherwise. These encounters exacerbate feelings of being ignored or not seen:

**“Make healthcare a place where people can be honest about who they are (in my instance, as a gay woman). Feeling unacknowledged and unseen can affect everything from diagnosis to treatment to supportive services.”** Participant 986: age 55–64, white, lesbian/gay woman, outside the UK.

Another participant explained:

**“My identity as a lesbian woman has been denied and also ignored. At one visit [my social worker] tried to insist that my ex-husband be contacted to help provide care for me. I have a restraining order against him because of his physical abuse of me.”** Participant 5, age 65+, white, lesbian/gay woman, England.

As reported in brief 2, one participant reported experiencing homophobia in the form of the attribution of symptoms to their sexuality:

**“Well, as specialists said my problems – chronic pain etc – were due to lesbianism I tried to make myself straight. This didn’t work.”** Participant 887: age 35–44, white, lesbian/gay woman, England.

For transgender people with ELC, the difficulties of accessing and getting good medical care are exacerbated by the broader difficulty accessing trans healthcare:

**“[My] GP did not believe I needed HRT as a post-op trans woman and withheld it for some months until I obtained a gender clinic letter telling them to give it.”** Participant 887: age 35–44, white, lesbian/gay woman, England.

In some cases the problems that transgender participants encountered weren’t just from medical professionals but also administrative systems:

**“I have been trying to get details changed with my doctor for five months because they changed my title on my records incorrectly without my consent (I am trans, changed it from Miss to Mr and then they later changed it again to Mx).”** Participant 316: age 25–34, white, bisexual, man, England.

## Body Size/Weight

Institutionalised weight stigma or fatphobia also has a significant impact on people’s access to healthcare. Of participants who answered the question, 15% 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:

**“As an adult, my lack of energy and frequent illness was written off as depression or anxiety or because I’m fat. I asked many times if it could be ME/CFS and was frequently told that that wasn’t a real thing, and I just needed antidepressants and exercise (when exercise made it worse, I just needed to stop being lazy and push through it).”** Participant 947: age 35–44, white, lesbian/gay woman, England.

In these encounters, reflections on people’s body size are not neutral and come laden with judgement. As the following participant explained, this undermines patients’ trust in the quality of care they receive:

**“When a health provider reaches for weight as an easy option – particularly if they are then also clearly being judgemental about my weight – I lose confidence in their objectivity and moral neutrality.”** Participant 688: age 55–64, white, heterosexual, woman, England.

This diagnostic overshadowing was even the case for one participant in the ‘healthy’ weight category whose medications caused weight gain:

**“Despite me being still in the ‘healthy weight’ category, my weight was constantly brought up. I lost count how many times I was told that chronic migraines are more common in obese people. I don’t know if that’s true or not, I do know that all but one [of the] medications I tried caused weight gain as their most common side effect, bringing into question the direction of causation in this case.”** Participant 616: age 25–34, white, bisexual, woman, England.

Experiences of fatphobia and diagnostic overshadowing were particularly common for the 180 survey participants with Lipoedema (a condition characterised by the abnormal build-up of fat in a person’s legs and arms). Of these participants (who answered the question) 65% had had their condition previously attributed to being overweight, obese, too fat, needing to lose weight, overeating, lack of will power, or ‘lifestyle factors’ related to weight. For many participants this led to the avoidance of medical care:

**“I never go to a [doctor] because whatever my illness or symptoms they always connect it to my weight. Tell me I’m fat and to lose weight and have no interest in my opinion or what’s actually the issue.”** Participant 82: age 35–44, white, heterosexual, woman, England.

As with other forms of disbelief which people encountered, the way that medical fatphobia operates to overshadow and preclude explorations of other possible diagnoses also leads to patients questioning their own understandings and experiences of their bodies, with negative implications for mental health (see brief 2 for more on the impact of disbelief on mental health):

**“When you’re obese, people are very judgemental and think you are lazy & can’t control what you eat. When you’re working really hard to lose weight but nothing is working, you start to question your own sanity thinking “am I lying to myself & others?! Am I just a pig who can’t control what they eat?!” This has led to me falling into a huge black hole of despair at times and “what’s the point of even trying?!” I now don’t bother to diet & exercise because the effects are so limited that “failure” causes my head to go into a downward spin.”** Participant 453: age 35–44, white, heterosexual, woman, England.

## Class/Wealth

While the original survey didn’t collect information about income, the qualitative data suggest that class and wealth do play a part in mediating the impact of disbelief and disregard.

Some participants explained that in addition to sexism, being working class or unemployed contributed to the disbelief or lack of legitimacy that they faced:

**“NHS have used my gender and working class, unemployed status to suggest that I am neurotic, somatising, have no insight into my illness etc., and that I am a pill seeker.”** Participant 79: age 35–44, white, heterosexual, woman, England.

After encountering disbelief from medical professionals in the NHS, some people who could afford to were able to get diagnoses by paying for private healthcare:

**“Over the years [I had] multiple issues addressed by multiple [healthcare professionals] and no one joined the dots. It took my own research and having to pay privately to see an expert before I was diagnosed.”** Participant 292: age 55–64, white, heterosexual, woman, England.

For some people this extends to treatment access too. For example, people with lipoedema often have to pay privately for liposuction to relieve their condition, because it is not available to them on the NHS:

**“I paid £18,500 for private ... liposuction but can’t afford to have more operations that I need.”** Participant 92: age 35–44, white, heterosexual, woman, England.

And this also extends to social care, where people aren't eligible for free care packages to meet all of their needs, and home visits for services such as dentistry and opticians:

**"I've requested help repeatedly from adult social services. I've been given living aids (recliner that stands you up, etc.) but no physical presence help and [I] have been told outright [that] if I want that I have to pay for it, [but] as I don't get help with mobility, I can't afford that."** Participant 779: age 45-54, white, asexual, woman, England.

**"The dentist could come out, but it is extremely expensive and I can't afford it. ... the optician was good, though there was no access to the cheaper frame ranges so I can't afford to use them again."** Participant 975: age 35-44, white, lesbian/gay, non-binary, England.

For people on low incomes or with multiple conditions, this may mean choosing which conditions to prioritise for private healthcare:

**"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.

Some participants also told us how living with ELC, and encountering disbelief from medical professionals, employers and benefit services has had a significant impact on their income, causing them to lose jobs, no longer be able to afford their bills or food, or resulting in homelessness (for more on this see brief 3 and 4).

For some participants, having family members who earned enough to support them was a privilege, but also gave them little independence or control over their own lives:

**"I felt awful having no income 'to my own name'."** Participant 247: age 45-54, white, heterosexual, gender non-conforming, England.

As the following participants explained, this lack of financial independence means it is very difficult for disabled people who are in abusive relationships to leave:

**"I would not be able to access disability benefits and services because I am a married woman (which also keeps disabled women in abusive relationships trapped)."** Participant 257: age 35-44, white, heterosexual, woman, England.

**"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

### 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.

### Listening and believing

Healthcare for people living with ELC must improve. 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

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.

## 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
5:2	"BMJ article" "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>