

# DISBELIEF AND DISREGARD

## GENDERED EXPERIENCES OF HEALTHCARE FOR PEOPLE WITH ENERGY LIMITING CONDITIONS



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

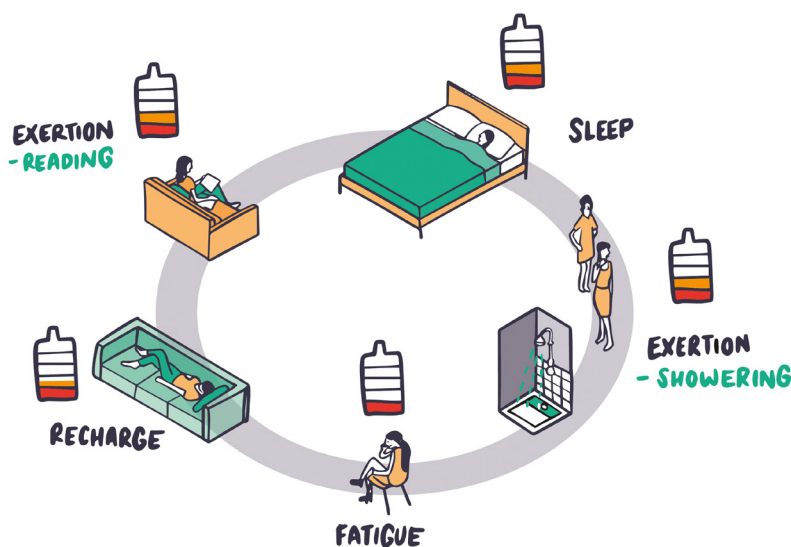
# BACKGROUND AND EXECUTIVE SUMMARY

BRIEF

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### Energy Limiting Conditions

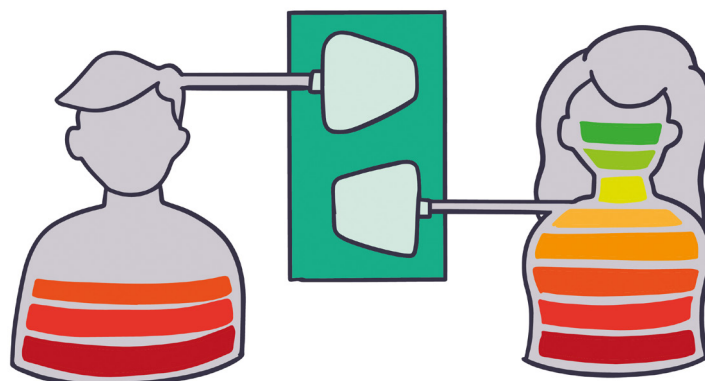
The term Energy Limiting Conditions (ELC) was established following [research by Chronic Illness Inclusion \(CII\)](#)<sup>1</sup>. It describes shared experiences across long-term health conditions in which energy impairment and debilitating fatigue are key symptoms. According to [estimates by the Department for Work and Pensions \(DWP\)](#), 1 in 3 disabled people in the UK experienced impairments in stamina/breathing/fatigue. These experiences are shared by people living with a range of conditions, including neurological, musculoskeletal, and autoimmune diseases, ME/CFS and fibromyalgia. The COVID-19 pandemic has significantly increased this population with, as of 1st October 2022, [around 2.2 million people in the UK \(3.4% of the population\) living with Long Covid](#). People with ELC are a large, overlooked section of the disabled population and one that is growing rapidly.



With ELC

FULLY CHARGED

Without ELC



### Gendered and Intersectional Experiences

Many ELC are more common in women, including Long Covid, ME/CFS, fibromyalgia, and many autoimmune diseases.

[Patriarchal attitudes](#) have been influential in the development of Western medicine, meaning women who live with these conditions have often been subject to

medical disbelief, their symptoms considered “medically unexplained” and/or dismissed as psychosomatic expressions of hysteria. Our research shows that such disbelief and disregard [isn't confined to history](#). These barriers to care are compounded for women of colour, LGBTQIA+ people, fat<sup>2</sup> people, and people at particular points in their life (e.g. puberty, menopause, old age) through intersections of sexism with racism, homophobia, transphobia, fatphobia and ageism. Our approach considers how these influence people's experiences

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

<sup>2</sup> In keeping with Fat Studies and Fat Activism, we use the word fat rather than overweight or obese to avoid pathologising on the basis of body size alone. Where quoting participants, we use their chosen terminology.

## Underpinning Research

These briefing documents present research exploring how people who identify as women, trans men, non-binary and gender non-conforming people with ELC experience healthcare.<sup>3</sup> In 2021, CII conducted a survey in response to the [DHSC inquiry into Women's Health and Wellbeing in England](#). The survey data from 962 participants record people's experiences in relation to healthcare, social care, employment, education and social and family life. The survey contained 14 open text questions, generating around 195,000 words of testimony about people's experiences. This project focused on analysing these qualitative data.

### Place of residence

Whilst the initial [report](#) written by CII focused exclusively on the 83% of participants living in England (given the remit of the DHSC inquiry), our subsequent research analysed all responses: 798 from England, 79 from Scotland, 41 from Wales, 11 from Northern Ireland and 33 from outside the UK.

### Gender

Participants largely identified as cis women (94%), 5% as transgender, non-binary, or gender non-conforming (including gender queer, gender fluid, and agender), and 1% preferred not to say.

### Race and ethnicity

91% of participants identified as White, 2% as Asian/British Asian, 1% as Black, African, Caribbean or Black British, 4% as mixed/multiple ethnic groups, and 2% as another ethnic group or preferred not to say.

### Chronic illness

The 962 participants shared experiences of over [40 different chronic health conditions](#), with 77% (n=743) of participants experiencing energy impairment.

## Summary of Key Findings: Pathway to Inequality

### Pathways to inequality

Our research points to a large, neglected population of people living with chronic conditions who face discrimination when seeking medical care. Negative experiences were shared by participants with a range of different energy limiting conditions. Discrimination, which manifests through disbelief and dismissal by healthcare professionals, has significant negative impacts on mental health, wellbeing and self-esteem; relationships with families and friends; exacerbates chronic illness; and acts as a barrier to people accessing welfare, benefits and social care, along with reasonable adjustments in employment or education. As such, this disbelief impacts every aspect of people's lives. A healthcare system that does not respond to the needs of people living with ELC worsens those conditions and contributes to the production and intensification of health inequalities that deserve much greater attention. For more information see brief 4.

### Neglect, harm and duty of care

The data reveal an alarming picture of medical neglect, disbelief, disregard and stigma



Pathway to Inequality

<sup>3</sup> Throughout these briefs we use the terms women or woman to be inclusive of all people who identify as women, including cisgender and transgender women. We also refer to transgender men as men. In addition to identifying as non-binary, there was a wide range of ways in which people described their gendered identities on the survey. We use the term gender non-conforming people here to include people who identified as gender queer, gender fluid, agender, atypical gender, and people who noted that they reject dominant gender concepts.

which significantly and negatively impact people's health and wellbeing. Negative experiences also erode trust and lead to healthcare avoidance, worsening energy limiting conditions and increasing health inequalities. Disbelief and disregard by healthcare professionals amount to an abdication of responsibility and duty of care towards people with energy limiting conditions. Ongoing allegiance to debunked paradigms is unacceptable. Ignorance in the face of evidence is unacceptable. For more information see brief 2.

## **Not listening to and/or not believing patients**

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. This number rises to 85% for LGBTQIA+ participants. 64% of people who answered the question said that they often or very often felt that their account of how their condition affects them was not believed by a health or care professional. For more information see briefs 3 and 5.

## **Delayed diagnosis**

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. While some conditions may not have clear diagnostic tests, it is evident in our data that a key barrier to quick diagnosis was the disbelief of healthcare professionals throughout the system. For more information see brief 3.

## **Misdiagnosis**

As well as being 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 is available following correct investigation. 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 a mental health diagnosis has become a catch-all for when doctors may not know a clear route to diagnosis, want to dismiss the complaint, or do not want to allocate further resources for investigation. For more information see brief 3.

## **Health inequalities**

Repeated experiences of being disbelieved and dismissed by healthcare professionals leads to an avoidance of healthcare, which exacerbates chronic conditions and health inequalities. Disbelief from medical professionals, and delayed or incorrect diagnosis have a broad impact on people's lives, influencing employers, social care professionals and benefit assessors. Medical disbelief therefore limits people's access to social care and benefits, along with reasonable adjustments for work or education. Of particular concern was the need to 'fight' to access even basic levels of care and support. This fight demands more energy than many people with energy impairment have available and increases social and financial inequalities. For more information see brief 2, 3 and 4.

## **Medical sexism**

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. For more information see brief 2.

## **Intersectional forms of discrimination**

Sexism encountered in healthcare is exacerbated for people who also experience ageism, racism, homophobia, transphobia and/or fatphobia. For more information see brief 5.

## **Inclusive research**

Patient and Public Involvement/Engagement (PPIE) can be a mechanism to promote greater inclusion, equality, and diversity in research and policy discussions. Often, however, PPIE activities are not accessible to people with ELC as such activities are too physically and/or cognitively demanding for people living with energy limitations and chronic pain. For more information and suggested ways to facilitate the involvement of people with ELC, see brief 6.

# **Recommendations: Pathway to Equality**

## **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

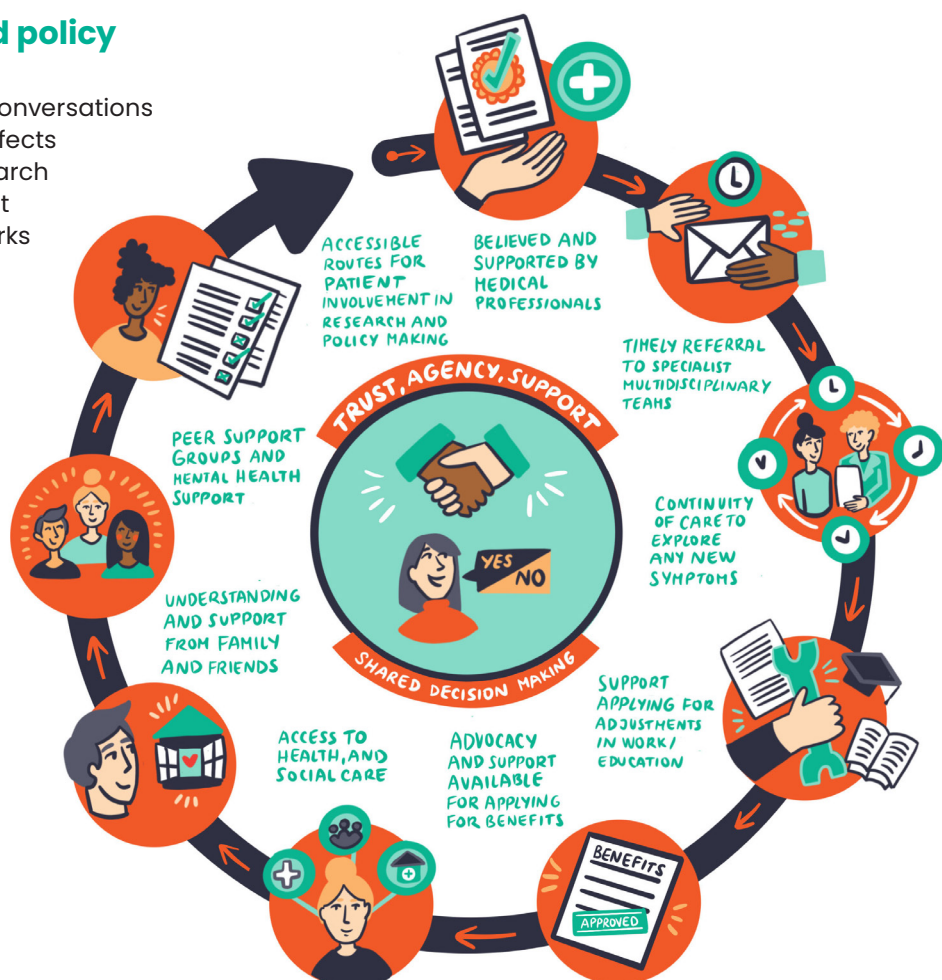
Institutional sexism continues to play a part in the poor quality of care many women with ELC face. Tackling institutional sexism in health, social care and welfare systems is essential but is also not enough. Intersecting forms of oppression, including racism, ageism, homophobia, ableism, transphobia 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>
1:1	"research by Chronic Illness Inclusion (CII)"	<a href="https://chronicillnessinclusion.org.uk/2021/04/28/what-are-energy-impairment-and-elci/">https://chronicillnessinclusion.org.uk/2021/04/28/what-are-energy-impairment-and-elci/</a>
1:1	"estimates by the Department for Work and Pensions"	<a href="https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2021-to-2022/family-resources-survey-financial-year-2021-to-2022">https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2021-to-2022/family-resources-survey-financial-year-2021-to-2022</a>
1:1	"around 2.2 million people in the UK (3.4% of the population) living with Long Covid."	<a href="https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1december2022">https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1december2022</a>
1:1	"Patriarchal attitudes"	<a href="https://www.bma.org.uk/news-and-opinion/closing-the-gender-health-gap-the-importance-of-a-women-s-health-strategy">https://www.bma.org.uk/news-and-opinion/closing-the-gender-health-gap-the-importance-of-a-women-s-health-strategy</a>
1:1	"isn't confined to history"	<a href="https://www.nice.org.uk/guidance/ng206/chapter/recommendations">https://www.nice.org.uk/guidance/ng206/chapter/recommendations</a>
1:2	"DHSC inquiry into Women's Health and Wellbeing in England" "report"	<a href="https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf">https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf</a>
1:2	"40 different chronic health conditions"	<a href="https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/Appendix-to-WHS.pdf">https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/Appendix-to-WHS.pdf</a>

## 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

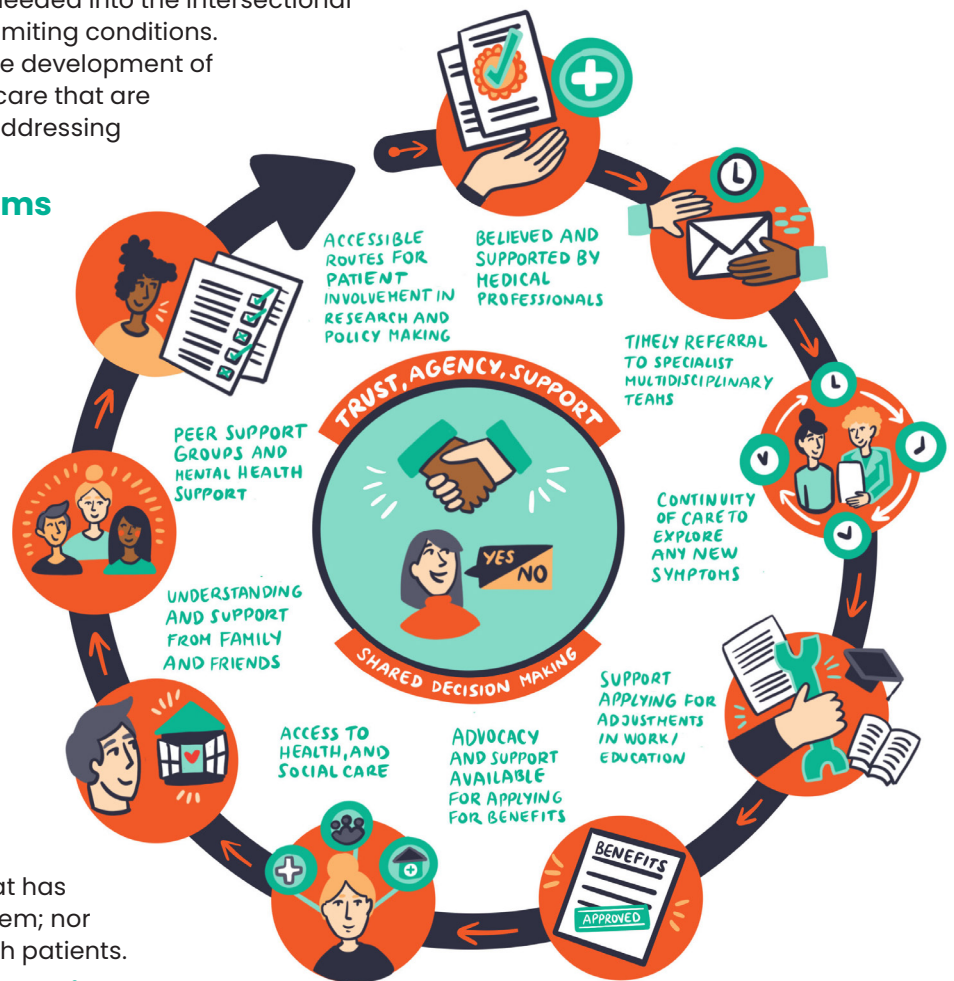
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### Inclusion in research and policy decisions

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## 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>



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

BRIEF 3

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

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] 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	<a href="https://www.gov.uk/pip">https://www.gov.uk/pip</a>



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

## PATHWAY TO INEQUALITY

### THE IMPACT OF DISBELIEF ON ALL AREAS OF LIFE

BRIEF 4

### Introduction

Our research shows that for people with Energy Limiting Conditions (ELC), being disbelieved by medical professionals has a significant impact on access to essential support in other areas of life, including social care, disability benefits, and reasonable adjustments in education and employment. In this brief we outline this impact and the ways in which it contributes to inequalities. For more information on the background and methodology used in this research, see brief 1.

### Domiciliary and Social Care

Of 367 participants who said they needed social care, only 5% said that the support they receive meets all of their needs. A further 24% said that it meets some of their needs and 24% said that they have requested social care but have been refused. People reported that access to care depended on a “postcode lottery” in terms of what services were available locally, and some reported loss of services that had previously been available because of budget cuts. Another 48% said that they need social care but they have not requested it. People had different reasons for not requesting support, but for many it was due to experiences of being disbelieved by medical professionals and feeling unworthy, embarrassed or not wanting to be seen to be making a fuss, because of years of disbelief (for further information see brief 2):



Pathway to Inequality



**“I don’t request because I couldn’t face being told no.”** Participant 434: age 45–54, white, bisexual, woman, England.

**“I have not requested it although have felt it would be better. But [at] this point I would rather start a flare [up] than the embarrassment of asking for it.”** Participant 228: age 45–54, white, heterosexual, woman, England.

Financial inequality is also a factor when people without sufficient resources are told to pay for services that they cannot otherwise access:

**“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 have been told outright if I want that, I have to pay for it. As I don’t get help with mobility [benefits], I can’t afford that.”** Participant 779: age 45–54, white, asexual, woman, England.

For many patients who are housebound by ELC, barriers to domiciliary care for routine tests and screening are exacerbated by disbelief from healthcare professionals:

**“I am housebound and needed some blood tests. My GP refused to believe I am housebound and repeatedly stated that I am ‘too young’ and that the district nurses were ‘too busy’ to come and take my blood. It took three appointments with different GPs in my surgery, and three months of phone calls, a complaint, my father to advocate for me, and a suggestion that they were breaching the Equality Act before they would refer me to district nursing phlebotomy services. I have also been unable to access home smear testing (my test is currently three months overdue).”** Participant 513: age 25–34, white, heterosexual, woman, England.

Along with the participant quoted above, 38% of the 138 respondents who considered themselves housebound or bedridden said they were unable to access domiciliary cervical screening. For some this meant not having had cervical screening for many years:

**“I’m told it’s impossible. I waited 5 years for a smear and only got it when I had a gynae scare and had to go to hospital for it. Even then as a wheelchair user they seemed to think I didn’t have a sex life and that a smear wasn’t important.”** Participant 685: age 45–54, white, heterosexual, woman, England.

**“I didn’t know you could have a smear test at home. I haven’t had one for some time because I can’t get onto the bed. I also didn’t know that dentists did home visits or that doctors could still do it! This information definitely needs to be shared with us all.”** Participant 125: age 45–54, white, heterosexual, woman, England.

Like the respondent quoted above, 60% said that they hadn’t requested domiciliary cervical screening, and many participants reported that they were unaware it was an option:

**“I was not even aware that it was possible to request most of these. I have simply gone without treatment for weeks or months until I have a period of improved symptoms and can go out to get care. The times I have requested home visits from GP have been refused.”** Participant 80: age 25–34, bisexual, England.

Ageism also plays a role in the denial of domiciliary care services to people considered ‘too young’ for them. Instead, people are advised to call an ambulance if they cannot get to the GP surgery, increasing pressure on emergency services:

**“I have requested home GP visits on several occasions when I’ve been too unwell to get to the surgery. I was told that home visits are only available to elderly people so because I am young I’m not able to get them. On these occasions I was unable to see a doctor for several weeks because I had to wait until I was feeling well enough to get to the surgery. This worries me a lot because I know if I’m too unwell to go out I have to call an ambulance instead of my GP.”** Participant 242: age 25–34, white, heterosexual, woman, England.

## Employment and Education

Of 785 people who answered the question, 46% said that their experience of being disbelieved by a health or care professional had a negative impact on their relationship with their employer and colleagues. In particular, the lack of a diagnosis or of backing from health care professionals made it difficult for people to advocate for themselves at work, in terms of taking time off during symptom flare-ups, and getting access to reasonable adjustments. In many cases diagnosis was the gateway to these adjustments:

**“Without formal diagnosis it was very difficult to make a case for the number of sick days I was taking. [Being denied] a formal diagnosis by the GP ... definitely had a direct impact on employers taking my symptoms seriously. After diagnosis my employer ...was incredibly supportive during [my] initial phased return to work ... I feel I could have been better supported prior to this [through] an earlier diagnosis that may have prevented over-working [when] I was really struggling. It would have also given me more confidence to have had discussions with work about reasonable adjustments.”** Participant 408: age 25–34, white, heterosexual, woman, England.

**“In the four years when I was undiagnosed, my supervisor would sometimes ask whether I had a diagnosis or not. I felt that she was using this to judge whether I was really as ill as I said I was, and therefore how much leeway she should give me. The fact that doctors wouldn’t take my illness seriously made it harder for my employer to take my illness seriously.”** Participant 901: age 35–44, white, bisexual, woman, England.

**“My employer is very good, but because I haven’t had a diagnosis, it’s hard to explain when I have a relapse of Long Covid.”** Participant 406: age 55–64, white, heterosexual, woman, Wales.

This was similarly the case for people in education:

**“Without a formal diagnosis I struggled to access disability related learning and exam adjustments at uni and school.”** Participant 547: age 18–24, British Asian, heterosexual, woman, England.

For some children and young people, disbelief from medical professionals led to their illness-related absences being attributed to truancy, and their parents reported to social services:

**“I have never been employed, however, my experience with healthcare professionals massively affected my school experience. Doctors were rarely the ‘safety net’ I needed to help me with a school that tried to report my parents to social services and treated me like I was truanting.”** Participant 580: age 18–24, white, heterosexual, woman, England.

Participants also reported that suspicion and disbelief informed by ignorance are significant barriers to adjustments in the workplace and in education:

**“My employer, [university name], has a narrow view of disability. They don’t understand energy limiting conditions and chronic pain. I feel like I have to regularly justify and ‘prove’ my health difficulties to access basic accommodations.”** Participant 864, age 25–34, white, bisexual, woman, England.

**“University refused to believe I was as sick as I was because I couldn’t prove it and wasn’t getting support.”** Participant 682: age 25–34, white, demisexual and bi/pan, non-binary, Scotland.

**“Headmaster and the school board refused my education because they didn’t believe I was sick.”** Participant 787: age 35–44, mixed-race, pansexual, woman, England.

For fluctuating conditions, this is made more difficult because of the changeable nature of symptoms:

**“Always difficult with a fluctuating condition. Employers often expressed the view that they’d been deceived by my seeming good health... I always felt unsupported in periods of poor health and often resigned, rested for a year or three then sought employment elsewhere.”** Participant 750: age 65+, white, heterosexual, woman, Scotland.

This is further exacerbated for stigmatised conditions in which the cause of illness has been wrongly associated with laziness, such as ME and Lipodema:

**“Because of the diagnosis and misconceptions about ME and the type of person who gets it my previously excellent relationship with my employer was destroyed. Even though previous appraisals noted I had an excellent work ethic and attitude, once you get a label of ME, that’s it.”** Participant 584: age 45–54, white, heterosexual, woman, England.

**“[Employers] think you are fat and lazy; [so you are] overlooked for promotion and other opportunities.”** Participant 117: age 45–54, white, heterosexual, woman, England.

For some people who would have been able to work with reasonable adjustments, being unable to access these meant they lost their jobs and with that, financial security and independence:

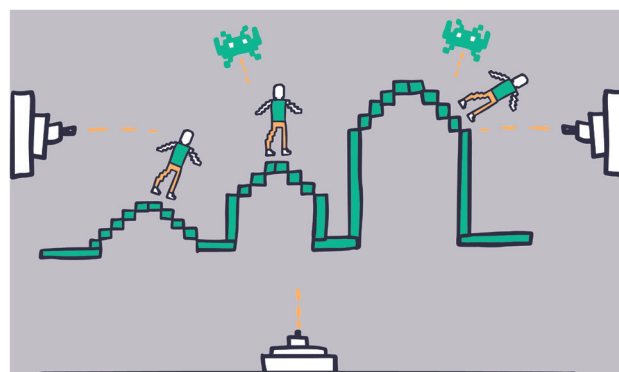
**“[I] lost my job and a career that I had excelled in because they wouldn’t allow me flexibility to work different times, from home, with support. I couldn’t even take them to court because I couldn’t afford to ... I have very little income so cannot socialise, save for the future, plan holidays, or pay for glasses I desperately need, dental care or clothes. I rely on handouts, and I just feel completely humiliated and worthless.”** Participant 429: age 45–54, white, heterosexual, woman, England.

## Benefits

Of 791 people who answered the question, 61% said that their experience of being disbelieved by a health or care professional had a negative impact on their access to disability benefits and services. For many people, disbelief from GPs in particular made benefit claims much more difficult:

**“Because my GP doesn’t seem to believe or understand how unwell/disabled I am I chose not to ask them for letters explaining my symptoms and conditions as evidence. This has made applying for benefits more**

**“ I CAN NEVER GUARANTEE THAT I AM GOING TO BE O.K AT A PARTICULAR TIME ON A PARTICULAR DAY ”**



## Fluctuation

**difficult. I do not even ask what services may be available for me, I know my GP wouldn't want to refer me to them."** Participant 596: age 18-24, white, asexual/demisexual, woman, England.

For respondents with Long Covid, the lack of acceptance that it may be a long-term condition also acted as a barrier to benefit claims:

**"I don't access any benefits or services at the moment. Long Covid sufferers tend not to hit the right criteria as no-one ... knows how long it will last."** Participant 279: white, heterosexual, woman, England.

Intersecting forms of oppression matter here for participants who also encountered racism as well as disbelief when trying to access benefits:

**"The whole system is institutionally racist, weaponised as such to prevent specific claimants acquiring what they need to survive."** Participant 31: age 55-64, woman, London.

Some participants were too afraid to apply for benefits because of the risk of being disbelieved and/or because going through the process would take more energy than they had available. Many participants talked specifically about claiming benefits as a "fight", with some having to go through multiple appeals, tribunals and getting MPs involved. When living with energy impairment, this fight may be too much:

**"I dare not apply, because they have created a hostile environment where they seem to approach ill people as if they are potential criminals. I can't cope with that. I read awful first-hand accounts of abuse towards applicants for PIP, etc. I am too scared to apply. I'm not well enough to go through that - it would terrify me."** Participant 235: age 55-64, white, heterosexual, woman, England.

**"I have not attempted to claim disability benefits, because (ironically) I feel too ill to face the fight this would entail. No longer in work, I am living off the stub of some savings; when these run out, I don't know what I will do."** Participant 318: age 55-64, white, heterosexual, woman, England.

For some who couldn't avoid going through this process, the 'fight' worsened their ill health and had a negative impact on their mental health:

**"Without a doctor's support, I have always been thrown back on the DWP's assessors, which in turn always leads to appeals and court action. The stress of this in itself has increased my level of disability substantially."** Participant 975: age 35-44, white, lesbian/gay, non-binary, England.

**"DWP give a lot of stress, exacerbating all of my conditions. Having won my tribunal 2 years ago, I have to go through it all again this year; I am deeply concerned."** Participant 108: age 55-64, white, heterosexual, woman, England.

Some participants therefore relied on friends, families or, where available, advocates to fight on their behalf, but many people do not have access to such support:

**"On one occasion my benefits were stopped just before Christmas because of a social worker. I was fortunate that my advocate was brilliant and sorted that out very quickly."** Participant 5: age 65+, white, lesbian/gay woman, England.

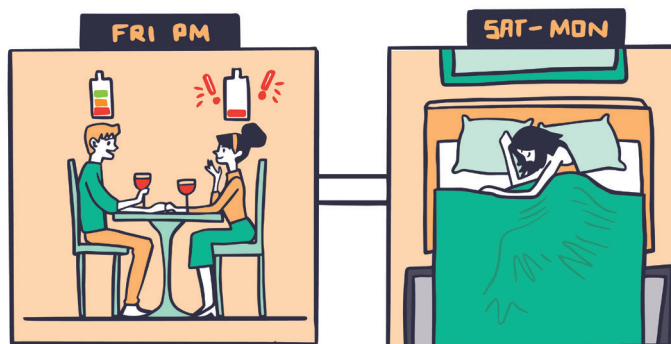
For some participants, having family members who earned enough to support them was a privilege, but also gave them little independence or control over their own lives. The lack of financial independence also means it is very difficult for disabled people who are in abusive relationships to leave:

**"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.

Participants spoke of the lack of understanding of ELC in the benefits system, and said that increased understanding of ELC is urgently needed, along with recognition that these long-term conditions can be exacerbated by the system itself:

**"I SOMETIMES GO BEYOND MY ENERGY LIMITS, EVEN THOUGH I KNOW I'LL PAY FOR IT AFTERWARDS"**



**Payback**

**“Allow PIP for proven long term chronic energy [impairment] so that we don’t have to keep working too many hours in order to pay for the times when we’re not working for months because of relapses. This cycling ruins our lives!! Yet a lot of us have no choice but to continually burn ourselves out to cope financially.”** Participant 519: age 45–54, white, heterosexual, woman, England.

**“The level of understanding in the disability benefits and support systems for energy limiting chronic illness is ludicrously poor. I am terrified every time a benefits review deadline is due for me because it feels like enforced Russian roulette. Am I going to get someone who understands nothing and who refuses to believe my limitations are valid or am I going to get someone decent who understands my condition? I feel like my level of impairment and struggle and suffering and need is completely irrelevant to trying to gauge what outcomes I can expect from the disability and benefits systems.”** Participant 290: age 35–44, white, woman, England.

## Recommendations

### 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.

### 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

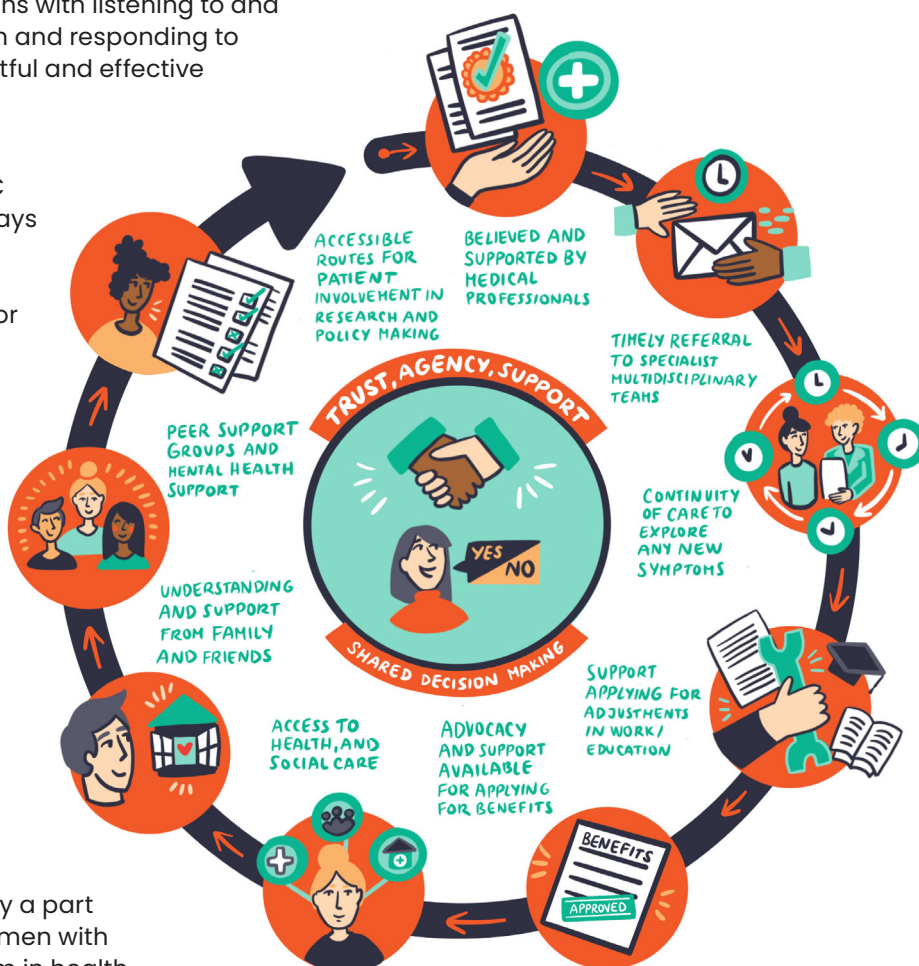
Healthcare for people living with ELC must improve. Better patient pathways and quality of care are needed for people with ELC. This includes the provision of appropriate treatment or symptom management, continuity of care and timely referral to multi-disciplinary and specialist services. In all of this,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



## Pathway to Equality

## **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)



## 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.

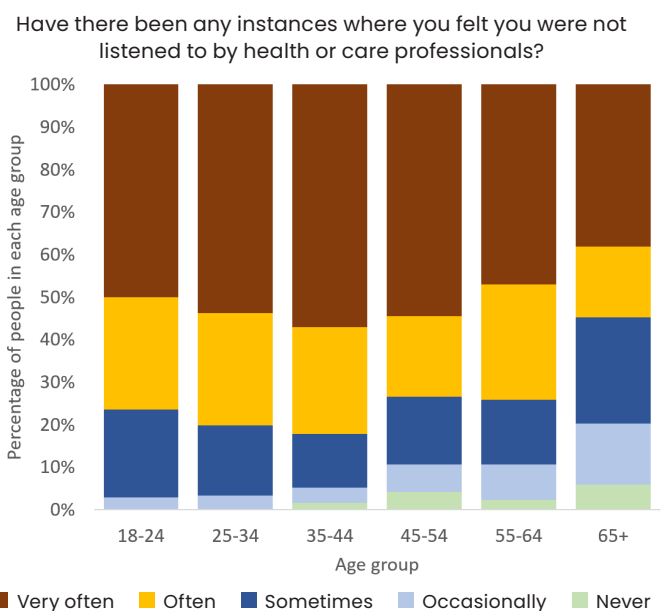
In the qualitative data, many participants now in older age categories said that they had faced disbelief when they were younger. Multiple participants reported having their symptoms dismissed as “growing pains”, “puberty”, “just being a teenager” or that they were told they were too young to be experiencing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

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

# “NOTHING ABOUT US WITHOUT US”

BRIEF  
**6**

## MAKING PUBLIC AND PATIENT INVOLVEMENT/ ENGAGEMENT (PPIE) MORE INCLUSIVE OF PEOPLE WITH ENERGY LIMITING CONDITIONS

### Introduction and Recommendation

One of the key recommendations from this research is:

#### **Inclusion in research and policy**

**decisions:** People with Energy Limiting Conditions (ELC) must be part of conversations about policy and practice that affect 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.

In this brief, we set out why we are making this recommendation and some suggested ways to make public involvement and engagement more inclusive of people with ELC. For more information on the background and methodology used in this research, see brief 1.

### The Need for More Accessible Modes of Engagement

Many of our participants told us that more research about ELC is sorely needed. This refers to a need for both more biomedical studies, and more qualitative research about the lived experience of ELC. This research must involve people with ELC and be used to influence conversations and decisions about healthcare policy, service development and practice.

People with ELC must be involved throughout the research process - from the conceptualisation and design stage, through to the analysis and dissemination of findings. One participant highlighted this need for more co-production of research:

**“Women need to be involved in every step of research processes - not just included as participants, but actively involved in designing the study processes. Without this, research will continue fail the people it is most meant to serve.”** Participant 68: age 25-34, white, bisexual, woman, England.



Patient and Public Involvement/Engagement (PPIE) is seen as a mechanism to promote greater inclusion, equality, and diversity in research. It is increasingly a key requirement of research funders when awarding grants. Our participants recommended involving people with ELC in patient engagement fora and ensuring their inclusion in wider conversations about healthcare policy and practice, in ways that enable their full participation. Some participants suggested establishing “experts by experience” panels where people with ELC could share their experiences with healthcare professionals, with a view to informing policy and practice. One participant explained:

**“I would like to see panels set up where people...with different healthcare issues and needs (ones which are poorly met at the moment, like mine) can discuss their experiences and feedback the improvements they would want to ideally see, to the relevant authorities.”** Participant 235: age 55–64, white, heterosexual, woman, England.

Another participant described the need for a “cultural shift” to ensure that diverse lived experience is given a higher priority within the research agenda:

**“We need a huge culture shift in women’s healthcare...investing in research for women’s health and drawing on women from all walks of life and actually listening to what they have to say.”** Participant 477: age 25–34, white, bisexual, woman, England.

There also remains a need to improve the accessibility of existing PPIE activities for people with ELC. Some of our participants explained that current PPIE activities are not accessible as they are too physically and/or cognitively demanding for people living with energy limitation and chronic pain, for whom cognitive fatigue is a common symptom.

## Recommendations to Make PPIE More Accessible to People With ELC

### Understanding of ELC

Embed understanding within PPIE of the unique challenges and barriers faced by people with ELC.

### Prioritising accessibility

Establish a supportive culture by prioritising accessibility and adapting involvement and engagement activities to take account of energy impairment. This may include (but is not limited to): online remote participation; shorter meetings with regular breaks; supporting people who need to participate with cameras off, or from darkened rooms; using accessible platforms and forms of communication.

### Asynchronous participation

Introduce asynchronous participation options. Even with access provisions in place, some people with severe ELC may not be able to participate in synchronous PPIE activities. Asynchronous activities enable people to contribute in their own time, over extended periods of time, as and when fluctuating conditions allow, taking into account the need to pace engagement.

### Minimising cognitive fatigue

Simplify tasks and provide clear written and recorded instructions to mitigate cognitive fatigue where possible.

### Financial support for participants

Budget time and resource to support the inclusion of people with ELC in PPIE. This includes reimbursement for participants’ time, covering costs for those who need the support of a personal assistant or carer, and advice about how payments for participation might have an impact on benefits.

**Further information** about improving access for people with ELC is available via Chronic Illness Inclusion here: [chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/remote-revolution-to-reasonable-adjustments.pdf](http://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/remote-revolution-to-reasonable-adjustments.pdf)

“LIKE A COMPUTER WITH TOO MANY TABS OPEN”



Cognitive Fatigue