

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

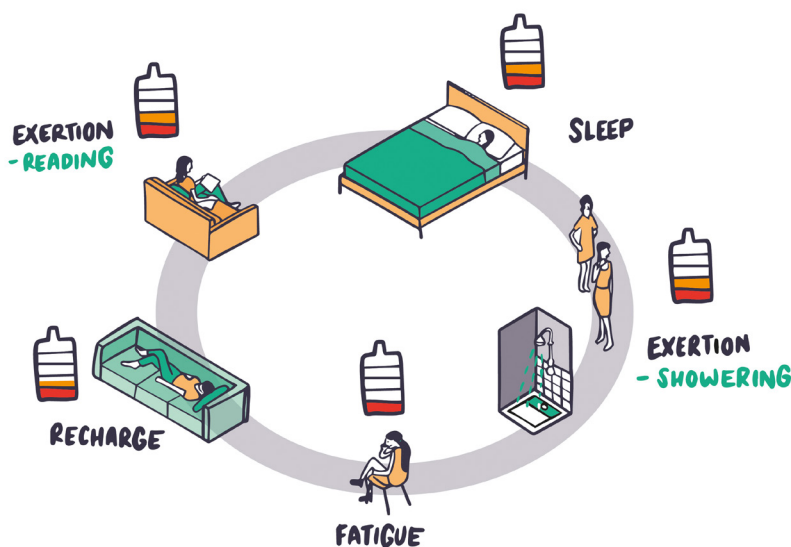
# BACKGROUND AND EXECUTIVE SUMMARY

BRIEF

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### Energy Limiting Conditions

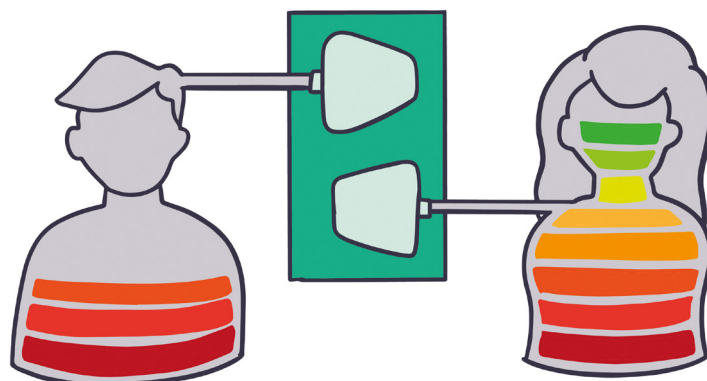
The term Energy Limiting Conditions (ELC) was established following [research by Chronic Illness Inclusion \(CII\)](#)<sup>1</sup>. It describes shared experiences across long-term health conditions in which energy impairment and debilitating fatigue are key symptoms. According to [estimates by the Department 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

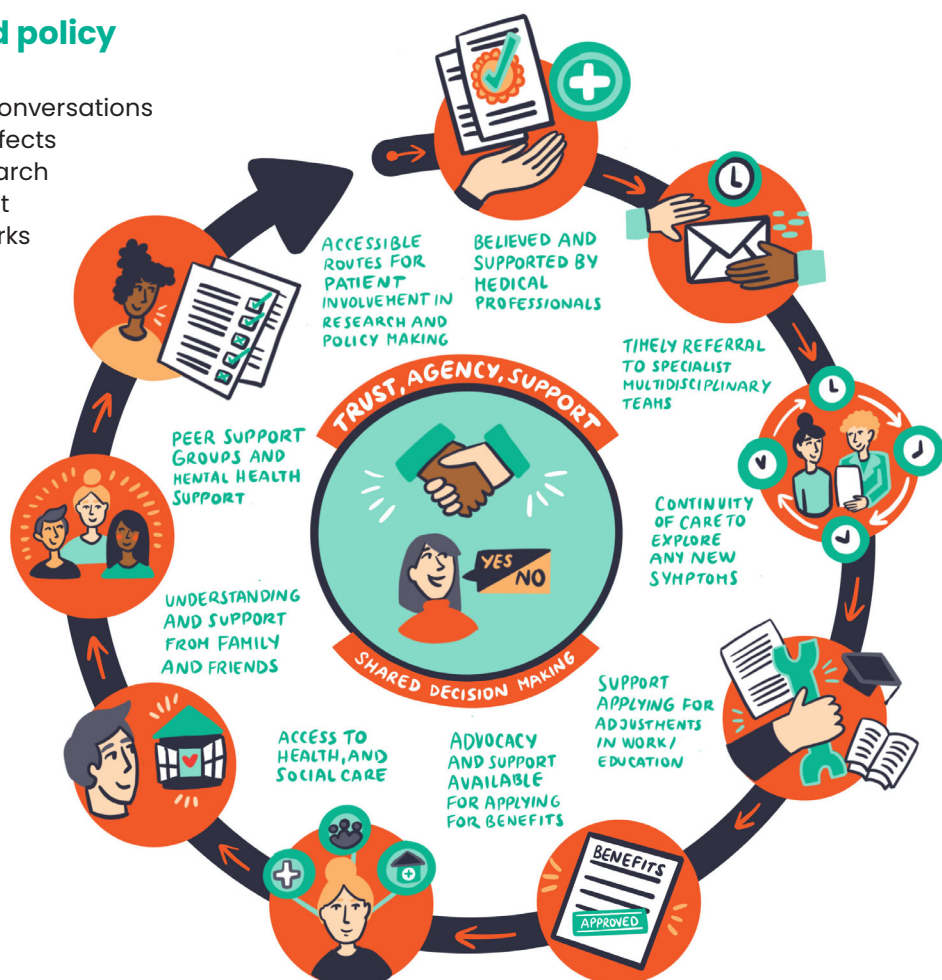
Institutional sexism continues to play a part in the poor quality of care many women with ELC face. Tackling institutional sexism in health, social care and welfare systems is essential but is also not enough. Intersecting forms of oppression, including racism, ageism, homophobia, ableism, transphobia 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>