

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:

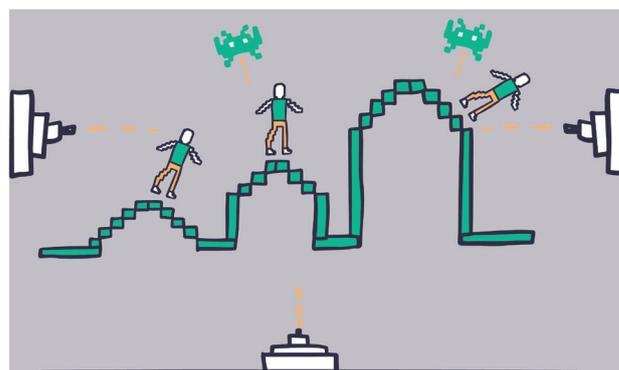
“[I] lost my job and a career that I had excelled in because they wouldn’t allow me flexibility to work different times, from home, with support. I couldn’t even take them to court because I couldn’t afford to ... I have very little income so cannot socialise, save for the future, plan holidays, or pay 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.

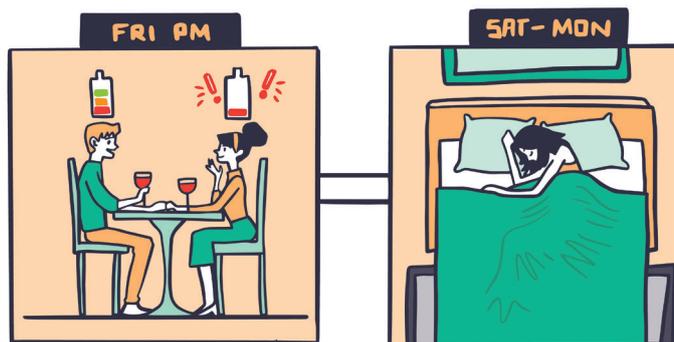
For some participants, having family members who earned enough to support them was a privilege, but also gave them little independence or control over their own lives. The lack of financial independence also means it is very difficult for disabled people who are in abusive relationships to leave:

"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)