



**CHRONIC
ILLNESS
INCLUSION**

**Submission to the
Department of Health and Social Care's
Inquiry into Women's Health
and Wellbeing in England**

June 2021





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Introduction

[Chronic Illness Inclusion](#) (CII) is pleased to present the results of a survey of almost 800 disabled women and non binary people in England living with chronic physical illness and their experiences of healthcare in the National Health Service (NHS). Most of our respondents lived with an energy-limiting condition, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia, or Long Covid.

CII is a Disabled People's Organisation. This means we approach chronic illness from a social justice, rather than a medicalised, perspective. Rooted in the social model of disability, we challenge the oppressive attitudes and exclusionary practices that diminish the lives of people with energy limiting chronic illnesses (ELCI) and chronic pain over and above their symptoms. We estimate that ELCI, or energy impairment, affects as many as one in three disabled people in the UK ([see a previous CII report](#)).

In 2018, our survey of over 2,000 disabled people living with chronic illness found improved healthcare to be respondents' highest priority for social change. At the same time, the most common source of ableist attitudes in their day-to-day lives was revealed to be healthcare professionals. This alarming finding clearly needs further investigation. CII therefore welcomes the Department of Health and Social Care's (DHSC) consultation as an opportunity to shine a light upon the healthcare experiences of women with ELCI and chronic pain, and identify any systemic barriers to healthcare equality for this group.

Alongside the quantitative data presented in this report, we received hundreds of open-ended responses. These responses merit a much more detailed thematic analysis than the scope of this submission allows, but their volume testifies to the urgent need to listen and respond to these experiences.

Executive Summary

The results of our survey paint a shocking picture of stigma, neglect, and woefully inadequate health and social care provision for disabled women with ELCI and chronic pain, with those who are housebound not even having their rights to basic healthcare upheld. The testimonies we received illustrate how neglect is deeply interwoven with disregard, invalidation, and disbelief of our respondents' lived experiences of illness and disability. This pervasive disbelief had an adverse impact on respondents' healthcare and wider lives, deeply affecting many aspects from relationships and employment to social security and personal relationships.

Report by Catherine Hale, Jennifer Brough, Alison Allam, Simon Lydiard, Fran Springfield, Aly Fixter, Nathalie Wright, Victoria Clutton and Kathy Bole.

A third of respondents had waited more than ten years for a diagnosis. The majority of disabled women who responded to our survey had energy-limiting health conditions, which are more prevalent among women and either difficult to diagnose (such as endometriosis, lipedema, and Ehlers Danlos Syndrome (EDS)), and/or poorly understood and often medically contested, such as fibromyalgia, Long Covid, and ME/CFS.

Before receiving their current diagnosis, four in five respondents had their physical symptoms attributed to various psychosocial causes by healthcare professionals (HCPs), such as anxiety, stress, or being overweight, and about a half had received psychological therapy, not for a diagnosed mental health condition, but to treat their undiagnosed physical symptoms. This is consistent with the approach to so-called Medically Unexplained Symptoms (MUS) within the NHS, which is to conflate MUS with somatisation, i.e., the manifestation of psychological distress through physical symptoms.

Respondents reported overwhelmingly negative impacts and outcomes from this MUS framework and treatment. They described the detrimental impact on their health and healthcare from effectively being labelled as an unreliable witness to their own bodies, as well as the psychological trauma of what many termed 'gaslighting'. We conclude that the MUS construct is not only logically flawed and contrary to the principles of patient-centred care, but is potentially hugely damaging to health and wellbeing. The MUS framework in the NHS must be critically interrogated. The voices and experience of patients and service users of psychological therapies for MUS must be heard, and these services must be evaluated, not just for their potential in reducing healthcare costs, but for their impact on patients' health and wellbeing.

Our findings strongly suggest that disabled women with ELCI and chronic pain are systemically disregarded in healthcare contexts, especially once labelled with MUS. Around 75% of respondents said they often, or very often, were not listened to, especially in relation to symptoms, treatment, and seeking referrals, rising to 90% for LGBTQ+ respondents. Respondents reported missed diagnoses of surgical complications, endometriosis, and lead poisoning, for example, as a result of not being listened to by HCPs. A significant number also reported a deterioration in their condition because their report of harm from MUS-informed treatment —notably graded exercise therapy for ME/CFS — was not listened to.

Fewer than one in five respondents felt supported by the specialist services for their health condition. They reported closed-mindedness of HCPs in considering alternative diagnoses once symptoms are labelled as MUS, and an unwillingness from HCPs to learn about emerging research into poorly understood diseases. The services that were available were often insufficiently accessible and were poorly coordinated in the case of multimorbidity, which was a common feature of respondents' impairment. Poor service wasn't restricted to specialist care. Support with symptom management was poor: nearly half said they could not access adequate pain relief, the same proportion couldn't access mental health support to cope with the distress caused by the impact of their health condition, and fewer than five percent had a social care package that met all their needs.

For the 20–40% of respondents who identified themselves as always (or sometimes) housebound reported an abject failure to provide the most basic healthcare services. The majority could not get a home visit from their GP and only a tiny minority received domiciliary dental care or sexual health screening. Many were utterly abandoned by the Health and Social Care system and leading 'invisible' lives. It is clear from the testimonies we received that disbelief in our respondents' impairment experiences was a key driver in the failure or refusal by healthcare providers to offer domiciliary services as a reasonable adjustment. Addressing the issue of healthcare equality and rights for housebound women, men, and non-binary people with ELCI and chronic pain is both urgent and long overdue.

Disbelief is the overarching theme of the testimonies we received. Around 62% of respondents said they were disbelieved by health and social care providers (HSCP) often or very often. Even when not explicit, disbelief was inferred by our respondents through attitudes of dismissal, disrespect, ridicule, and denial of care. We conclude that this disbelief was not only a result of individual failings by HCPs but is a systemic issue, driven by the healthcare system's response to medical uncertainty — as exemplified in the MUS framework. Disbelief had wide-ranging implications on the lives of our respondents. Apart from causing missed or delayed diagnoses, disbelief breaches the therapeutic relationship between HSCPs and patients, leading patients to fear and avoid seeking healthcare in future. Disbelief by professionals profoundly affects confidence, self-esteem, and agency. It can impact families and the very relationships on whom we depend for care and support. Disbelief by HSCPs causes further disadvantage because entitlements to social security and social care support very often hinge upon the validation of impairment by a HCP. Without a validated impairment we struggle to assert our status as disabled people and access our rights to disability equality, at work and within society. We need HSCPs not just to believe us, but to vouch for our impairments — even if they cannot be measured — because our fundamental social and economic rights depend on it.

As we have no comparable data for men's healthcare experiences, our survey does not allow us to determine whether the stigma, disbelief, and neglect reported by our respondents was a direct result of their gender. They may have resulted from systemic sexism in the healthcare system's response to conditions which are more prevalent among women, in which case disabled men with ELCI and chronic pain may be similarly impacted. What is clear is the need to redress the self-perpetuating cycle of disbelief, lack of medical knowledge, and neglect. A properly resourced programme of biomedical research into hard-to-diagnose and poorly understood diseases that predominantly affect women is vitally needed. Our respondents expressed a strong desire to be involved in the design and implementation of such research as well as be research subjects.

Because disbelief by HSCPs is systemic and diminishes lives far beyond the symptoms of disease itself, we understand it to be disabling in terms of the social model of disability. It is unsurprising, therefore, that disabled people with chronic illness refer to disbelief in their impairment experience as 'ableism'. Above all, the shocking findings of this report is to respect CII's principle of *nothing about us without us*. Listening to, and believing, the lived experience of disabled people is necessary to achieve an understanding of their healthcare needs, which is the first step to meeting them.

Key evidence from our survey

Who took part in our survey?

This submission includes the voices of 798 women living in England, including trans women, non-binary and gender non-conforming individuals. Of that number, 29% were lesbian or bisexual women and 9 in 10 were white. Around 92% per cent of respondents were disabled under the Equality Act provisions, with 68% reporting "severe" disability. (See [Methodology Appendix](#) for more detailed demographic information about respondents).

Four in five respondents reported their impairment type as 'energy impairment', i.e., stamina or fatigue. Of these, 80% also reported problems with mobility, 58% with memory, and half noted problems with learning, understanding, or concentrating. Roughly 55% reported a comorbid mental health condition, indicating that ELCI involves multidimensional impairment. The most frequently reported conditions were ME/CFS, irritable bowel syndrome, fibromyalgia, migraine, musculoskeletal condition, asthma, lipedema,

EDS, postural orthostatic tachycardia syndrome, and hypothyroidism. Of our sample, 7% had symptoms of Long Covid ([See Table 2](#) for all conditions).

1. Diagnostic delay and “Medically Unexplained Symptoms”

“They were giving me talking therapy because they thought it was a factitious or exaggerated disorder, so all the focus was on [...] stuff like my parents divorce, rather than aspects that could have been useful like how I was coping with symptoms”

The largest group of respondents (31.29%) waited for more than 10 years to receive a diagnosis. Only 25% were diagnosed within 12 months. The majority (51.45%) were eventually diagnosed by an NHS specialist. Lipedema, EDS, and ME/CFS were the three conditions with the longest diagnostic delay.

78% were given one or more ‘psychosocial’ explanations for their physical symptoms before obtaining their diagnosis, most commonly stress (34%), depression (33%), anxiety (29%), and challenging life events (24%). Significant “other” responses included being overweight. Many respondents were refused care when symptoms were attributed to their weight and were blamed if they were unable to lose weight. **Only 3% found these attributions of their physical symptoms helpful and 66% said they were “not at all helpful”.**

51% of respondents were referred for either a talking and/or behavioural therapy to address their physical symptoms (rather than a diagnosed mental health condition). This is consistent with treatment offered by the Integrated Access to Psychological Therapies (IAPT) programme for so-called Medically Unexplained Symptoms (MUS) within the NHS. Within this framework, the term MUS is used synonymously with ‘somatisation disorder’, ‘somatoform disorder’, ‘functional disorder’, and similar terms implying illness of psychological origin. Only 15% of these found psychological therapy for their physical symptoms very or somewhat helpful. **81% found psychological therapy for MUS unhelpful; of which 63% said they found it ‘very unhelpful’.**

Themes arising from 312 respondents’ open-ended responses about psychological therapy for MUS included:

- 1) Talking therapy was sometimes helpful for adjusting to the impact of a health condition, but did not help alleviate physical symptoms.
- 2) The sense that patients were being blamed or “treated like a timewaster” because medical science did not have any explanation or answer to their suffering.
- 3) Receiving treatment within a psychologist-led service causes a further diagnostic delay for existing or additional health conditions because all reported physical symptoms are interpreted through the ‘somatisation’ paradigm, i.e., as manifestations of psychological distress.
- 4) Psychosocial attribution for physical symptoms when not aligned with lived experience feels frustrating, insulting, and offensive. Many respondents used the term ‘gaslighting’ in this context.
- 5) Psychological therapy for MUS sometimes causes health to deteriorate, either from the exertion of attending a service, or as a direct result of an intervention like graded activity or exercise for ME/CFS or Long Covid.
- 6) Although MUS is usually a tacit diagnosis, once patients are labelled as such by referral to psychological therapy for MUS, GPs are less likely to listen, believe, or take their symptoms seriously in future.

2. Having our voice heard

The largest group of respondents (51.3%) said they ‘very often’ felt they were not listened to by health or care professionals, with a further 23.28% saying that felt this way ‘often’. Only 2.46% never felt that they were not listened to. This experience of being disregarded occurred most commonly in relation to: discussing symptoms (81.60%), discussing treatment options (68.99%), and seeking referral to a specialist (66.32%).

Our evidence suggests experiences of being disregarded may be compounded by transphobia and homophobia. Respondents who identified as non-binary or gender non-conforming were more likely to report that they were not listened to “very often” (58%) or “often” (32%), compared to cis gendered women (51% and 23% respectively). Lesbian and bisexual women experienced not being listened to “very often” (55%) and “often” (28%) compared to heterosexual women (51% and 22% respectively). There was no significant difference in the experiences of BAME women compared to their white counterparts, probably due to small sample size, however seven women cited racial discrimination as a factor in their healthcare experiences in qualitative data.

We received 890 separate comments about experiences of not being listened to. The main themes were:

1. Once symptoms have been attributed to psychosocial factors, HCPs refuse to listen and refuse to investigate and treat physical illness, leading to diagnostic delay.
2. Patients with contested diagnoses, or who were previously labelled with MUS, are not listened to when developing new symptoms.
3. Healthcare staff refuse to listen to patients or learn from them when presented with new scientific knowledge about certain conditions for which they lack knowledge or training.
4. Diagnoses of serious illness or injury are missed as a result of HCPs not listening to, or dismissing, patients’ accounts of pain:
“My bladder problems were caused by surgical complications, but doctors attributed this to ‘lesbianism’, ‘poor hygiene’ and other things for some years before admitting the problem.”
“Seeing a neurologist about then-unknown causes of neurological problems. He insisted I was ‘worrying my pretty little head too much’ and it was all psychosomatic. Turned out 18 months later that I had lead poisoning.”
“I went to many doctors trying to get endometriosis diagnosed... One doctor told me she thought I was just lonely after I documented my pain.”
5. Disregarding patient’s testimony by HCPs often occurs in relation to negative impacts or side effects from treatment, whether from medication or behavioural interventions, as well as in relation to symptoms. This can also lead to serious harm, especially so in relation to graded exercise therapy for ME/CFS.

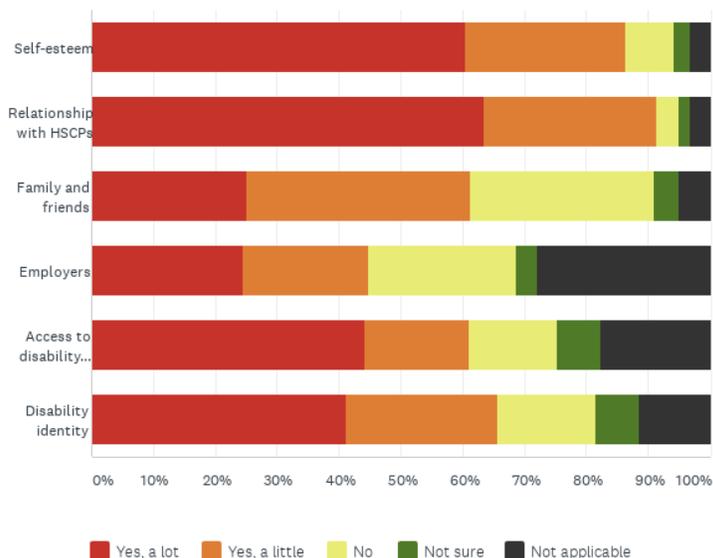
3. Disbelief and its disabling impact

Our survey asked about being believed as well as being heard. Around 40.8% of respondents ‘very often’ felt their account of how their condition affects them was not believed by a HSCP, while 21.32% said they experienced disbelief ‘often’. Disbelief is sometimes explicit but often implied:

“Negative responses to my diagnoses have ranged from derision to aggression, some showing indifference; neither challenging me nor acknowledging it. I have to assume disbelief.”

These experiences of disbelief mainly related to General Practitioners (81.86%), with another large group (49.61%) citing a specialist doctor, and a smaller group citing a social care professional (20.47%).

Q27 Negative impacts of disbelief



We subsequently asked what the impact of being disbelieved by HSCPs had on other areas of their life, as well as on their health and wellbeing. **The largest impact of disbelief was on subsequent relationships with HSCPs and on self-esteem, with around 90% reporting a negative impact in these areas.** More than 60% reported that disbelief by HSCPs had a negative impact on their relationships with friends and family, access to disability benefits, as well as their identification as a disabled person. The impact of disbelief on employment relations was less marked (below 50%), but almost 30% said this question was not applicable to them. Below, we briefly summarise common themes:

Self-esteem, confidence, and wellbeing (329 comments)

“The experiences caused me to doubt myself and to blame myself for not having advocated for myself more effectively. I feel weak and insignificant and uncared for.”

- Feeling socially worthless
- Feeling ‘gaslighted’
- Experiencing distress and anger
- Doubting and blaming themselves
- Developing anxiety in response to disbelief by HSCPs
- Undermining their ability to advocate for themselves in all areas of life
- Feeling undermined across every area of their life

“Being disbelieved makes you question everything you know about yourself and your conditions and leads into a dystopia which undermines everything in your life.”

Relationships with health and social care professionals (375 comments)

- Fear and dread of interacting with HSCPs in case of new symptoms or increased needs *“I now dread any interaction [with social workers] and have less care than I need because I'm scared to ask for more”.*
- Avoiding healthcare, or keeping interactions to a minimum, and struggling to trust HSCPs. *“I have zero confidence and have spent years unable to cope with doctors.”*
- Disbelief of symptoms and their impact often means required adjustments and accommodations are refused.
- Disbelief leads to inappropriate responses to patient distress, especially if related to contested conditions: *“A consultant told me fibromyalgia was a hindrance and not life-ending like cancer, go make some friends and don't moan... no one likes a moaner.”*

Relationships with family and/or close friends (294 comments)

- Partners are less willing to provide care and unconditional support, sometimes causing relationships to breakdown.
- Disbelief causes family members to blame the patient for their condition, including due to lack of willpower, e.g., with eating.
- Staying away from family members or friends because it's 'too exhausting' to negotiate disbelief and distrust.
- Difficulty trusting anyone but close friends who believe them, leading to increased social isolation.

Employment relations (270 comments)

- Microaggressions of disbelief from co-workers are described as exhausting and distressing: *“The whispers about my needs, the glances of obvious disbelief, the 'but you look well' comments”.*
- Employers have a narrow view of disability which creates an additional obstacle to reasonable adjustments: *“They don't understand energy limiting conditions and chronic pain. I feel like I have to regularly justify and “prove” my health difficulties.”*

There were 314 additional comments about the impact of disbelief in health and social care regarding access to disability benefits, and 289 comments about how disbelief is internalised and prevents them from identifying, and knowing, our rights as disabled women. Although beyond the scope of this submission these themes are an important testimony to the damaging impact of invalidation and disbelief on our lives.

4. Experiences of specialist healthcare and social care services

‘I can't get any support. Nothing. And after many years of trying, I am giving up. The system is too hostile, over-stretched, under-resourced and difficult to access.’

Only 17% of respondents said they felt supported by the specialist services available for their particular condition or disability. Main themes in the 462 comments about specialist services include:

- The lack of any specialist services for their health condition means many respondents were left with no care or help at all. Many said there was 'little point' in them trying to access healthcare.
- Existing services tend to be based on prejudiced and stigmatising views about certain patient groups, i.e., women, or poorly understood. Doctors are not adequately trained or informed about biomedical research into conditions such as ME/CFS. These services often offer potentially harmful treatments such as graded exercise therapy and can cause mental distress.

- The healthcare system needs to be made more accessible to those with ELCI. Waiting lists are long; appointments are too short for complex cases to be heard; appointments need to be scheduled at the right time of day, and video conferencing should be an option. The environments in medical centres are often inaccessible for patients who need to lie down and are sensitive to stimuli, such as light and noise.
- There is a lack of joined-up care, oversight, and referral to other support services, especially for those with comorbidities. Patients are left struggling to navigate a complex system without the energy to fight. Continuity of care with regular check-ins and help to access mental health support, benefits help, and social care should be standard.

Other services

Only 2.14% said they got social care and support that met all of their needs. Of the 315 people that had care needs that were not met by informal care, 150 had not requested social care support, 74 had been refused it, and 77 received social care support that only partially met their needs.

28.27% disagreed and a further 25.84% disagreed strongly that they received adequate pain relief. Over half of respondents reported a mental health condition secondary to their physical health condition. When they received CBT aimed at the mental health challenges of living with a physical health condition this was generally helpful. Yet **a large proportion of respondents (48.86%) disagreed or disagreed strongly that they had received the mental health support they needed.** The majority of respondents (52.42%) disagreed strongly or disagreed with the suggestion that they had received the help they needed in seeking a referral to a specialist.

5. Healthcare inequalities for housebound and bedridden patients

“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.”

For the purposes of this survey, we define ‘housebound or bedridden’ as either: 1) being always or sometimes unable to leave the home to get to a medical appointment even with support or assistance, or 2) the exertion from leaving the home to attend a medical appointment would result in significant worsening of symptoms, flareup, relapse, or setback as a consequence, e.g., for days or weeks.

According to this definition, 18% of respondents considered themselves completely housebound, whilst 36% said they were ‘sometimes’ housebound. The fluctuating nature of many ELCIs means people who are sometimes and unpredictably housebound require flexible arrangements for altering appointments:

“I have had to cancel multiple appointments when flares have made it impossible to leave the house. Unfortunately, the unpredictability of my conditions means I often don’t know I’m going to be bedridden until the day of the event, making requests for home visits basically impossible.”

Only 12% of respondents had ever received a home visit from their GP. Fewer than tow percent had ever received a domiciliary dental or sexual health screening service, and only five percent had accessed domiciliary dental care.

The most frequent themes from 161 respondents’ comments about requesting or receiving domiciliary services were:

- Respondents who requested a domiciliary service are often refused not only a home visit but even a telephone call.
- Respondents were often unaware that they may be entitled to request a domiciliary service as a reasonable adjustment.
- Fear, shame, or hopelessness often prevented respondents from requesting a domiciliary service.
- Requests for a domiciliary service were often refused on the basis of denial that the patient was housebound because the impact of their symptoms was not believed.
- The failure to offer domiciliary services as a reasonable adjustment means housebound patients are unable to access essential health prevention and screening services.

6. Comments on research, evidence, and data on women’s health and healthcare

Respondents were invited to comment on the themes of research, data, and evidence relating to women’s health and healthcare. The most common theme arising in these comments was a demand for more, and better quality, research into causes and treatments for conditions that are more prevalent among women. Many felt they received poor treatment because their condition(s) predominantly affects women. Their experiences of disbelief, derision, and dismissal affected their trust in the NHS and in the information provided on their condition by the NHS.

Many worried that they weren’t properly supported because their condition presents differently in women than in men, and expressed a wish that treatments and medications were tested more extensively on women. Some felt the answer to this bias is to have more female researchers in the field of medical research. Several respondents expressed a strong wish to volunteer as research participants in a study about their condition.

Conclusions and recommendations

Our survey suggests that the construct of MUS is frequently applied to disabled women with ELCI and chronic pain, especially with hard-to-diagnose or poorly understood diseases. Because MUS is conflated with somatisation disorder, their physical symptoms are effectively attributed to psychological distress or social factors without evidence of a mental health condition. The women we heard from reported overwhelmingly negative impacts on their health and wellbeing from MUS frameworks and treatment, including diagnostic delay and missed diagnoses, as well as the psychological trauma of ‘gaslighting’. As discussed, the construct of MUS is flawed because it precludes the possibility that a diagnosis has been missed or that medical scientific knowledge about a disease entity is incomplete. We conclude from this research that the somatisation model of MUS systemically silences the voices of disabled women with hard-to-diagnose or poorly understood diseases, and discredits their lived experience of impairment. This prevents them from self-advocating effectively in their healthcare and is in striking opposition to principles of patient-centred care embraced by the NHS. It also breaches the fundamental principles of the Disabled People’s Movement: *Nothing About Us Without Us*. We, therefore, urge that the somatisation model of MUS be called into question. In particular:

- **The voice and experiences of patients labelled with MUS must be heard. More research is urgently needed into service users’ experience of psychological therapies for MUS.**
- **Patients’ experiences of harm from psychological therapies for MUS must be believed. The Medicines and Healthcare products Regulatory Agency’s Yellow Card scheme for reporting harm must be extended to psychological and behavioural interventions.**

- MUS services must be evaluated, not only for their stated aim of reducing healthcare use and costs, but for their impact on the health, wellbeing, and functional status of patients.

Disabled women with ELCI and chronic pain reported uniformly poor, and often shockingly inadequate provision, both from primary and specialist healthcare services. As well as lack of effective specialist treatment, they are often denied adequate symptom management, social care support, and, ironically, support for the mental health impacts of living with their impairments. In addition, multimorbidity is very common among disabled women with ELCI and chronic pain, but siloed healthcare systems leave them battling a disjointed service alone and exhausted. This neglect appears to be strongly connected to the fact that, once labelled with MUS, respondents are almost routinely disregarded and disbelieved by HSCPs. We believe this interconnected neglect and disbelief of women is perpetuated by the lack of investment into biomedical research and treatment for diseases that predominantly affect women.

- We call for proper investment in biomedical research into hard-to-diagnose and poorly understood diseases that predominantly affect women to break this cycle of disbelief and neglect.**
- In the meantime, a change in the attitude of HCPs in the face of diagnostic uncertainty is needed. Disabled women with ELCI and chronic pain must be listened to, believed, and empowered to play an equal role in their healthcare decisions and symptom management. HCPs must be trained to be open and honest about the limits of medical scientific knowledge and approach uncertainty in a spirit of scientific inquiry.**
- We call for better care coordination for disabled women with ELCI and chronic pain, especially in the context of multimorbidity. We also need better integration of healthcare with social care, welfare rights support, and mental health support.**

Healthcare inequalities and breaches of women's healthcare rights occurred most acutely among those who are housebound. Once again, disbelief and invalidation of their impairment experiences was a key driver in the failure or refusal to offer domiciliary services as a reasonable adjustment for many respondents to our survey. Disbelief by HSCPs has a far-ranging impact, including on access to social care, social security, and employment relations, as well as on psychosocial well-being. We conclude that disbelief is not only caused by individual failings among HCPs but is systemic — rooted in our healthcare system's response to medical uncertainty. In the terms of the social model of disability, this systemic disbelief is damaging because it restricts and diminishes lives far beyond the impairment itself. This may explain why disabled people with chronic illness have previously described their encounters with HCPs as 'ableist'.

- We demand domiciliary primary healthcare services for housebound disabled people as part of our fundamental human right to healthcare.**
- We call for much more flexibility in service provision and accommodation to healthcare environments as a reasonable adjustment to fluctuating, energy limiting conditions, especially those with sensory sensitivity.**
- HCPs have a duty to proactively support our claims for social security and social care support, regardless of whether the medical technology exists to measure our impairments.**

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