

REMOVING SOCIETAL BARRIERS FOR DISABLED PEOPLE WITH ENERGY- LIMITING CONDITIONS

Findings from a survey on social change among people with energy-limiting chronic illness and energy impairment by Chronic Illness Inclusion and Disability Rights UK.

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Executive Summary

Introduction

One in three disabled people in the UK lives with an energy limiting condition or impairment. Building on the work of the Chronic Illness Inclusion Project, Disability Rights UK and Chronic Illness Inclusion (CII) surveyed our members and supporters about the next steps we need to take for this growing constituency of disabled people in a post-Covid world.

We heard from 1,710 people with a variety of health conditions and impairments, 80% of whom identified as disabled. The high volume of responses to our survey provides us with a mandate, as well as a roadmap, for social justice and change from disabled people living with energy-limiting chronic illness (ELCI) and other forms of energy impairment. We henceforth use the term energy-limiting conditions (ELCs) to cover both groups.¹

Our findings clearly show that the vast majority of disabled people with ELCs encounter socially constructed barriers to wellbeing and participation in society, beyond the impact of their symptoms or impairment. Many of the barriers are unique to this group.

The greatest barrier to equality and inclusion named by our respondents is lack of understanding of ELCs as a type of disability. Second is the invalidation and disbelief that so often accompanies this ignorance. Alongside this, more than four in five respondents reported barriers, at least 'to some extent' to education, healthcare, income security, getting out and socialising with friends and family. Like other disabled people then, people with ELCs face inequalities across most areas of their lives.

Call for solutions

¹ Many disabled people with energy limiting conditions identify as 'chronically ill', rather than, or as well as, 'disabled', and prefer the term energy-limiting chronic illness (ELCI) to define their type of disability or impairment. Some disabled people identify as having energy impairment that is not due to a chronic illness. In order to encompass both groups we henceforth use the term 'energy-limiting conditions' (ELCs).

It comes as no surprise that, among the solutions demanded by people with ELCs, improved awareness and understanding of the lived experience of energy impairment **as a type of disability** was by far the most common theme. Respondents called above all for a programme of education about ELCs aimed at employers, disability benefit assessors and decision makers and policy actors. Another key group mentioned in relation to education was healthcare professionals. The stigma of disbelief and the dismissal of lived experience was too often traced back to the medical approach to ELCs. Healthcare staff need much better training in supporting patients with complex, debilitating and often poorly understood conditions to live as well as possible.

Environmental and other barriers to access and participation also need addressing. Many of the solutions are relatively simple, including more seating, less ambient noise, easier access to Blue Badge scheme, for example. Employment opportunities for people with ELCs can also be increased by relatively simple flexible working solutions such as remote working. The Covid19 lockdowns showed us how easily this can be done when the collective will is there.

The need to reframe perceptions of ELCs throughout society underpinned most of the solutions offered by our respondents. Until ELCs are seen and understood as a type of disability, the adjustments and accommodations needed for greater access and inclusion will remain off the disability inclusion menu and out of reach of those who need them.

Respondents called for much better systems in place to provide income security to those who cannot work full time, and support with daily living to empower them to contribute to society. These measures are crucial to ensure talent and potential are not lost to the brutal battle for day to day survival that traps so many lives. Disability assessment systems for PIP, ESA and social care must be redesigned to capture the lived experience of impairment. Disability policy making and service planning must include the ELC impairment group as a major constituency among its stakeholders.

The need for an alliance for ELCs

We found that the people experiencing energy impairment face the same structural and systemic barriers regardless of their different diagnoses. This explains why they identify with the umbrella term of energy limiting chronic illness (ELCI), or ELC. This tells us that we must pool our efforts across patient representative organisations to secure social justice and disability rights for this group, not focus purely on medical solutions.

Previous research has shown that people with ELCl are often unsure if the label of 'disabled person' applies to them and a high proportion report feeling like an imposter if they identify as disabled.

Until we pay more attention to disabled people's lived experience of impairment, rather than their diagnostic label, those with ELCs will remain invisible, marginalised and neglected as a group.

The tragic emergence of Long Covid as an enduring legacy of the pandemic makes the case for action even more urgent. We must now act together, with stakeholders from various ELC communities alongside disability rights experts, to strengthen and deliver rights and support for people with energy limiting conditions so they are not left behind.

A large majority of our respondents expressed an interest in joining a panel of experts by experience to influence policy and advocate for change. Almost 1,000 of them volunteered their contact details to hear of opportunities to get directly involved.

Key findings

- Three quarters of respondents said that energy impairment was the main restricting feature of their condition.
- People with a range of medical diagnoses, including Long Covid, fibromyalgia, ME/CFS and lupus, face the same structural barriers and injustices.
- Lack of understanding of ELCs was cited as a barrier to inclusion by 98% of respondents. This was closely followed by attitudes of disbelief in their health condition or impairment, at 95%.
- 9 in 10 respondents reported barriers to paid work, as well as informal ways of contributing to society, socialising with friends and family, accessing healthcare services, cultural and leisure facilities, and getting out and about generally.
- 8 in 10 respondents reported barriers to income security, including through the benefits system and over three quarters to accessing social care.
- The call for increased awareness and understanding of the lived experience of energy impairment as a *type of disability* was mentioned nearly twice as often as any of other types of solution for change.
- Other key themes in the call for solutions were: access to public spaces and events, including online participation; more genuinely flexible working opportunities; improved systems of financial support for those unable to work full-time and the provision of support with daily living

tasks; and a culture change among healthcare professionals' attitudes to ELCs, including training the latter to understand the lived experience of energy impairment and support patients to live as well as possible with poorly understood chronic health conditions.

- Changing perceptions of ELCs and shaping policies to include ELCs were the top priorities in terms of working for change.
- Three quarters of our respondents replied 'yes' or 'maybe' to joining a panel of experts by experience to be involved in creating change.

Introduction

Disability Rights UK and Chronic Illness Inclusion are pleased to present the results of a survey of 1,710 people living with energy-limiting conditions (ELCs). This survey builds on the work of the Chronic Illness Inclusion Project, part of the ground-breaking DRILL programme between 2017 and 2020. Findings from previous CIIP research suggest that 1) people with ELCs are a discrete, but overlooked, impairment group, and 2) there is an urgent need for advocacy work focused on issues of social justice rather than purely medical solutions to chronic illness.

This paper takes as a given that ELCs are, by definition, disabling, and that people living with ELCs are disabled people. In fact, one in three disabled people in the UK lives with an energy limiting condition, according to research by the Department for Work and Pensions (DWP).² The time to focus on this large, but in many ways hidden, group of disabled people is now.

Austerity policies since 2010 have meant restricted eligibility to disability benefits and social care. As a result, the question of who is, and who is not, a "genuine" disabled person has never been more highly charged. Previous research³ shows that, like other 'hidden impairment' groups, people with invisible, and medically ill-defined, ELCs are often not identified as disabled people. More than ever, they are seeing their entitlement to vital support cut, and their rights as disabled people called into question.

In addition, over a million people in the UK were living with Long Covid in October 2021, according to the Office for National Statistics.⁴ More than a

² <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020>

³ <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/energy-impairment-and-disability-inclusion.pdf>

⁴

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsa>



third reported 'severe disability'⁵ and fatigue was the most reported symptom. This means we are seeing a significant new cohort of disabled people with ELCs who may not be fully aware of their rights in relation to work, economic security and independent living.

Our survey ran from the 3rd to 25th September 2021. Our questions were framed by the social model of disability. We asked people about the structural and systemic barriers to their wellbeing and participation in society. Most importantly, we asked them, in their own words, for solutions to dismantling these barriers in order to promote equality and inclusion for ELCs. We also asked whether they, themselves, wished to play a part in achieving the change they want to see.

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⁵ Severe disability is indicated by respondents reporting that their activities are 'limited a lot'.



Who did we hear from?

This report is based on an online survey between the 3rd and 25th of September 2021. It was disseminated by a range of organisations including Chronic Illness Inclusion, Disability Rights UK, Astriid, MEAction UK, MEAction Scotland, Long Covid Support Employment Group, ME Association and others.

Impairment

74% said **energy impairment or fatigue was a main restricting feature** of their health condition(s) or impairment.

25% said energy impairment or fatigue was a secondary feature of their condition or impairment.

The concepts of energy impairment and ELCI are closely aligned with 'impairment of stamina, breathing, or fatigue' (SBF), which is reported by approximately 1 in 3 disabled people of working age in the UK, equivalent to around 7% of the population.

CIIP research found that energy-limiting chronic illness and 'energy impairment' is the preferred language of self-identification among disabled people with impairment of stamina or fatigue.⁶ Yet neither these, nor the category of SBF impairment, is regularly used by the government to collect evidence or inform policy on social security, employment, education, social care or any other areas of policy involving disability. This is because disability policy-making and practice are hampered by a medical model of disability which considers ELCs only by individual diagnosis, not by shared lived experience of impairment.

Until we pay more attention to disabled people's lived experience of impairment, rather than their diagnostic label, those with ELCs will remain invisible, marginalised and neglected as a group.

Health conditions

Table 1: reported health condition(s) and impairments in order of frequency. Respondents could tick more than one condition.

⁶ <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/energy-impairment-and-disability-inclusion.pdf>

ME/CFS	42.28%
Fibromyalgia	42.05%
Chronic pain condition	41.64%
Other (please specify)	37.43%
Mental health condition	32.69%
POTS/dysautonomia	14.74%
Hypothyroidism	13.63%
Other neurological condition	13.22%
EDS/HSD	12.46%
IBD (eg Crohns Disease)	8.42%
Long Covid	7.37%
Lupus (SLE)	7.08%
Other physical impairment	2.69%
Multiple sclerosis	1.64%

ME/CFS, fibromyalgia and chronic pain were the most frequently reported diagnoses. A mental health condition was reported by almost a third of respondents. Previous surveys by CII strongly suggest that around 2 in 5 people with ELCs experience comorbid⁷ mental distress. The lower frequency

⁷ Denoting or relating to diseases or medical conditions that are simultaneously present in a patient.

of Long Covid, lupus and multiple sclerosis is likely due to the dissemination methods used.

The most frequently reported “other” conditions were rheumatoid arthritis, osteoarthritis, chronic migraine, endometriosis, asthma, irritable bowel syndrome, complex regional pain syndrome, mast cell activation syndrome, degenerative disc disease, diabetes and functional neurological disorder.

Disability identity

80% considered themselves to be disabled. 14% were unsure.

Although a strong majority of respondents considered themselves to be disabled, previous research by CII shows a high level of ambivalence and ambiguity among this group about openly identifying as disabled, accompanied by public hostility. In a previous survey of over 2,000 people with ELCs, around 60% said they feared negative reactions from others if they identified as disabled, and 43% agreed with the statement: ‘I feel like an imposter if I identify as disabled’.

Moreover, a shocking 92% of this previous cohort said they always or sometimes get told that they don’t look disabled, and 64% avoided asking for help or support because they feared being dismissed as fraudulent.

This shows a clear need to address public perceptions of ELCs and of disability generally.

Socially constructed barriers

We asked: *In which of the following contexts do you experience externally imposed barriers or unnecessary restrictions, other than your symptoms or impairment itself?* The answer options were “a great deal”; “to some extent” and “not at all”.

The most common barriers encountered ‘a great deal’ were to employment (64%), contributing to society outside formal employment (56%) and accessing cultural and leisure activities (50%). If we look at barriers overall, however, it is striking that more than four in five respondents reported barriers, at least ‘to some extent’ to education, healthcare, income security, getting out and socialising with friends and family. The exception to this trend was in the area of housing, with almost half of respondents saying they encountered no barriers at all.

We can infer from these findings that disabled people with ELCs encounter a high level of structural and systemic injustice, in addition to their inherently restricting symptoms. Externally imposed restrictions are very significant and present across most aspects of their lives.

In CIIP research conducted in 2018, more than four in five of over 2,000 respondents with ELCs agreed that better understanding of, and accounting for, chronic illness would significantly improve their quality of life.

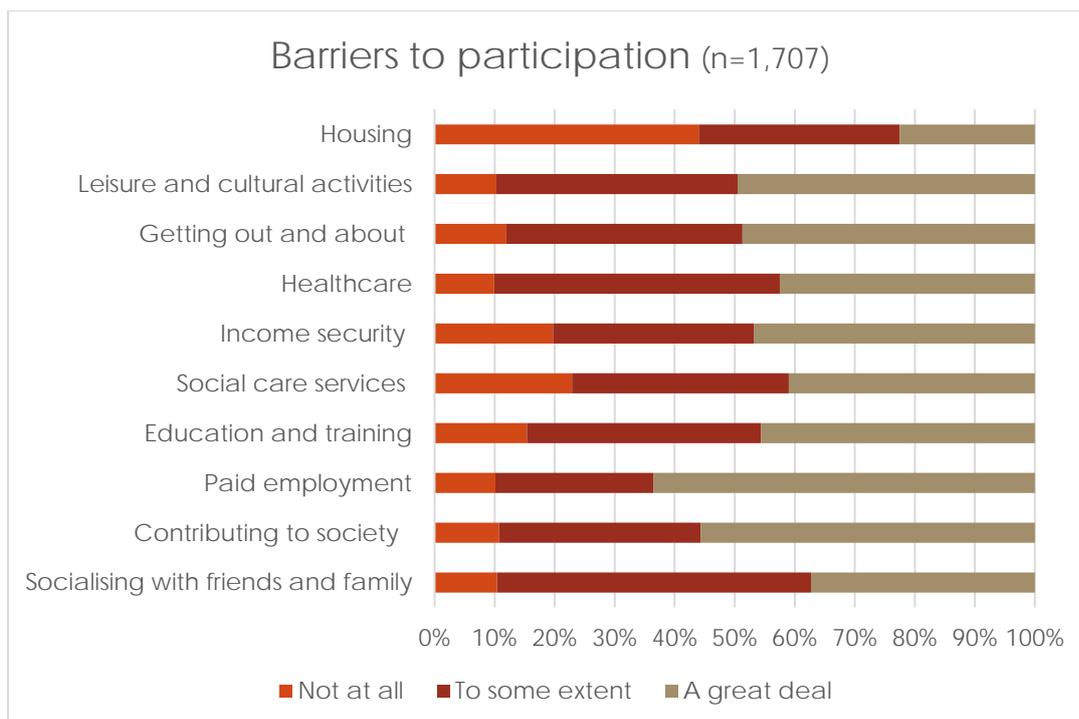


TABLE 1: BARRIERS FACED "A GREAT DEAL" FROM HIGHEST TO LOWEST

	A great deal
Paid employment	63.73%
Contributing to society	55.91%
Leisure and cultural activities	49.64%
Getting out and about (access to public transport and public spaces)	48.96%
Income security and social security benefits	47.02%
Education and training	45.85%
Socialising with friends and family	37.53%
Healthcare	42.70%
Social care services (getting assistance)	41.24%
Housing	22.68%

Types of barriers

We asked: *Thinking of all the contexts listed above, which, if any, of these types of barriers or restrictions do you experience?* Answer options were "a great deal"; "to some extent" and "not at all".

The social model of disability argues that barriers to equality and inclusion for disabled people can be environmental, organisational, or attitudinal.

The two types of barriers encountered a 'great deal' by our respondents were attitudinal ones. Lack of understanding of chronic illness was reported as occurring 'a great deal' by 85% of respondents, and disbelief by 65%. These attitudes are clearly linked.

Environmental and organisational barriers also featured 'to some extent' for almost 90% of respondents.

The attitudinal barrier of disability discrimination, including hostility and low expectations towards disabled people, was also encountered 'to some extent' by a high proportion of respondents but less so than lack of understanding and disbelief.

We can infer from this that the social oppression experienced by disabled people with ELCs is not so much because we are disabled but because society refuses to accept that we are disabled.

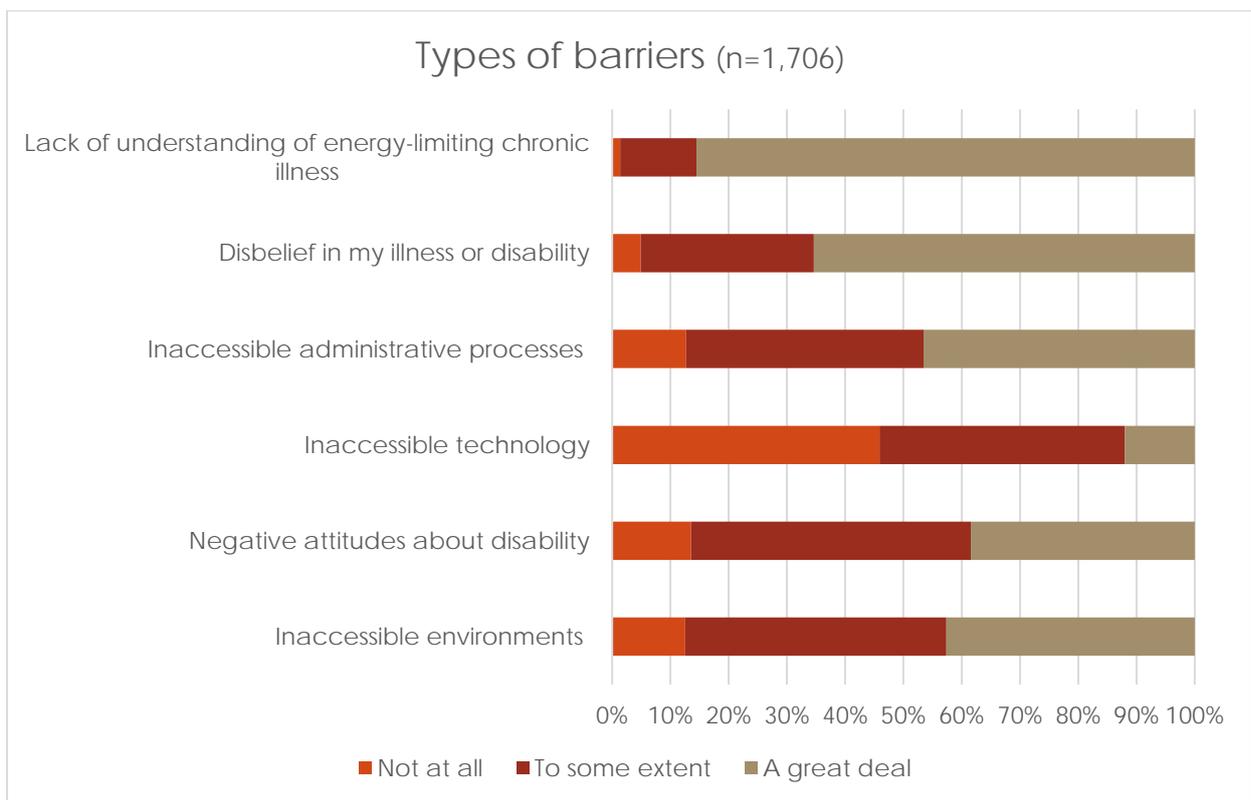


TABLE 2: TYPE OF BARRIERS ENCOUNTERED "A GREAT DEAL", FROM HIGHEST TO LOWEST

	A great deal
Lack of understanding of energy-limiting chronic illness or energy impairment	85.67%
Disbelief in my illness or disability	65.70%
Inaccessible processes (bureaucracy, systems or policies)	46.73%
Inaccessible environments (eg lack of wheelchair access, noise levels)	42.80%
Negative attitudes about disability (eg low expectations, hostile attitudes)	38.57%
Inaccessible technology	11.99%

Solutions for improving life chances with ELCs

We asked: *Please tell us your top 3 solutions for improving the lives of people with energy-limiting health conditions or impairments.* Thematic analysis was carried out on 410 (26%) of the 1549 open-ended responses received to this question. We are presenting all the solutions here in order of preference by respondents. See Appendix for a list of themes and sub-themes in order of frequency.

Raising awareness and improving understanding of ELCs

“Awareness training for practitioners and bureaucrats in health, education, welfare and disability sectors so that energy limitation is understood and can be taken into consideration in planning and decision making.”

“A big campaign that teaches people what ableism is, and that some disabilities are invisible.”

“Understanding. Empathy. Being believed.”

The broad theme of raising awareness, improving understanding and educating the public and professionals about ELCs **as a type of disability** was present in the open-ended responses almost twice as often as any other theme.

Respondents called for “*Acknowledgement of fluctuating conditions and flares*”; “*Understanding that I may appear ok when I am doing something but then I can suffer extreme pain/tiredness for days after which is not seen*”; “*Educating the public on how debilitating fatigue can be*” and “*More understanding for the general public that not all disabilities are visible.*”

Alongside this they called for “*Recognition as a disability*” and “*Parliamentary classification of these conditions as disabilities which will allow wider recognition and proper funding.*”

This theme underpinned many of the other solutions offered by respondents. For example, educating professionals about ELCs was mentioned in relation to employers, healthcare professionals and assessors or decision makers for disability benefits.

A strongly linked theme to this one was the need for people with ELCs to be listened to, respected and, above all, believed.



After this theme, the following four themes received approximately equal mention: getting out and about and participating; healthcare services, employment and income security including social security benefits.

Getting out and taking part

“It would be great to use my blue badge or accessible toilets without being scared of the response of others and potentially having to justify why I am using them.”

“Continuing online options after the pandemic response. I've been able to see and engage in more things and noticed how much this stopped once things opened up again.”

The second most frequent theme was improving access to public spaces, including transport and events. Respondents wanted to see much more seating in public spaces: *“More places to sit down in towns and in nature.”* ; along with provision of quiet spaces for resting and recharging energy while out and about, eg *“Rest stops in supermarkets and places where there are queues.”* They wanted more public toilets and disabled parking bays; less unnecessary ambient noise and music in shops and restaurants: *“Quieter and less scented environments would be helpful.”*

They called for Blue Badges and mobility aids to be much more readily available and accessible and for venues and transport to be fully accessible to wheelchairs and mobility scooters. Another common theme was online access to events and cultural activities: *“I would like alternative access to groups, classes, training or volunteering opportunities such as online based participation or ‘anytime access’ (so you can go back and watch/participate again another time if you aren't up to the activity on a particular day or time).”*

Many of these provisions and adjustments are withheld not due to cost per se but due to questioning, suspicion and judgement about the veracity of their need. Respondents were clear that a change in public perceptions of ELCs must underpin all other changes: *“We need recognition in public spaces equal to people with a visible disability.”* A part of this must involve raising awareness of the cognitive dimension of ELCs, as well as the physical difficulties it causes: *“We need aids to daily living for people with energy limitations, that take into account not just physical limitations, but also limitations in cognitive activity.”*

Improved healthcare services

“Doctors need to diagnose people quickly. No diagnosis results in having benefits refused and lack of support.”

“Belief from doctors that fatigue (in my case from Long Covid...) is real.”

“Digital health innovations to provide high quality health care and social inclusion that are readily available to people who struggle to leave home.”

Many ELCs are poorly understood by medical science. Their symptoms often cannot be measured or verified by existing technology, and there are no curative treatments. Whilst some respondents called for a re-prioritising of investment into research into these neglected diseases, the majority who mentioned healthcare solutions called for specific improvements to existing healthcare provision, even in the absence of new treatments or cures.

They wanted faster diagnosis, much better care coordination, the provision of alternative therapies where there is no conventional treatment, and better mental health support. They strongly supported an expansion of telehealthcare services where appropriate, for specialist services as well as GP appointments.

The key to these improvements, they said, is for healthcare professionals to receive training in the lived experience of ELCs, to understand the impact of these conditions on daily living: *“We need better understanding of the impacts of energy impairment by doctors and welfare providers.”*

Most respondents mentioned the need for a change in attitudes from disbelief and dismissal of symptoms to one of listening, respect, partnership and support, even if the cause of a condition is not currently understood, because *“The number of times I’ve been told it’s in my head is that many times too much.”*

More inclusive employment opportunities

“Genuinely flexible working that allows for rest and fluctuating symptoms.”

“More flexible work-from-home jobs.”

“The ability to contribute and be rewarded in a meaningful way.”



The solutions offered in relation to paid employment were remarkably consistent. Respondents called overwhelmingly for more genuinely flexible employment opportunities, by which they meant the provision for working from home and with flexible working hours to accommodate fluctuations in their symptoms and energy levels. The Covid19 lockdowns have demonstrated how easily these elements of flexible working can be achieved if there is the will to do so. They also called for *"quiet places to sit or lie down in the workplace."*

"Financial assistance to help me keep working" was another common sub-theme. Respondents wanted to be able to afford to work part time. Many stated that the benefits system does not adequately compensate disabled people financially for needing to work part time due to their health condition. As a result, they face the stark choice between full time work and being entirely dependent on benefits.

Once again, these solutions were very often accompanied by the call for greater awareness and understanding of ELCs as a type of disability by employers, as well as Human Resources and Occupational Health professionals. *"Remove barriers created by employers' Sickness Absence processes, and other inflexible HR processes"* and *"return to work plans are genuinely helpful to both parties"* were among the concrete changes called for.

Changing perceptions of ELCs was often seen as the first step to accessing workplace adjustments and creating a culture of inclusive work.

Improve income security and the benefits system

"If we got better recognition of our illness and less disbelief of our symptoms...more help and support to keep people in work but with better protection, if we do have to go sick then you would have less people being totally unable to work and claiming benefits."

"Adequate social security benefits so that the despair and stress of poverty is not an additional issue on top of ill health."

"PIP & ESA assessment changes to reflect the daily struggles of those living with energy limitations."

Respondents wanted to see changes to the administration of the benefits system, the level of benefits, the descriptors used in disability assessments and the awareness and understanding of ELCs among assessors and decision makers.



They called for a system that supports health, wellbeing and participation in society. The administrative burden of making and maintaining claims including repeat assessments, *"when they know your condition will not get better or deteriorate"*, the convoluted appeals process, the struggle to obtain medical evidence, and the short deadlines for returning forms were all mentioned as needing addressing. This was summed up by one respondent as *"Simplifying the process of applying for disability benefits so that it requires less of our already limited energy and is less cognitively taxing."*

Respondents called for a level of income that allows them to participate in society rather than being pulled further away from a purposeful and socially connected life by poverty: *"Improve support for people who are unable to work, or who become unable to work or lose their jobs through their illness."*

Above all, the descriptors and eligibility criteria for disability benefits need to take account of the lived experience of ELCs. *"Better understanding of chronic pain conditions by doctors & assessors for social security benefits"* was called for. The lack of accounting for lived experience was inextricably linked with the hostility and disrespect associated with the current system. Respondents wanted *"not being made to feel like a liar constantly"* and wanted *"A kinder benefits system that supports rather than acts like you are on trial."*

Social care and support

"Access to support - either occupational therapy or social services or carers - without a massive fight."

"Social care should be about living life, not just being clean and fed."

The fifth most common theme for solutions was the need for support and assistance in the home. *"Social care to help with household energy zapping tasks"* as one respondent put it, was felt would greatly improve quality of life. There were calls especially for *"increased access to carers, cleaners and affordable pre-cooked food"* and *"support with housework, shopping and cooking,"* as well as *"support for families and with childcare"*. A key sub-theme here was the need for a support worker or advocate *"to help with housing, benefits and childcare issues"*.

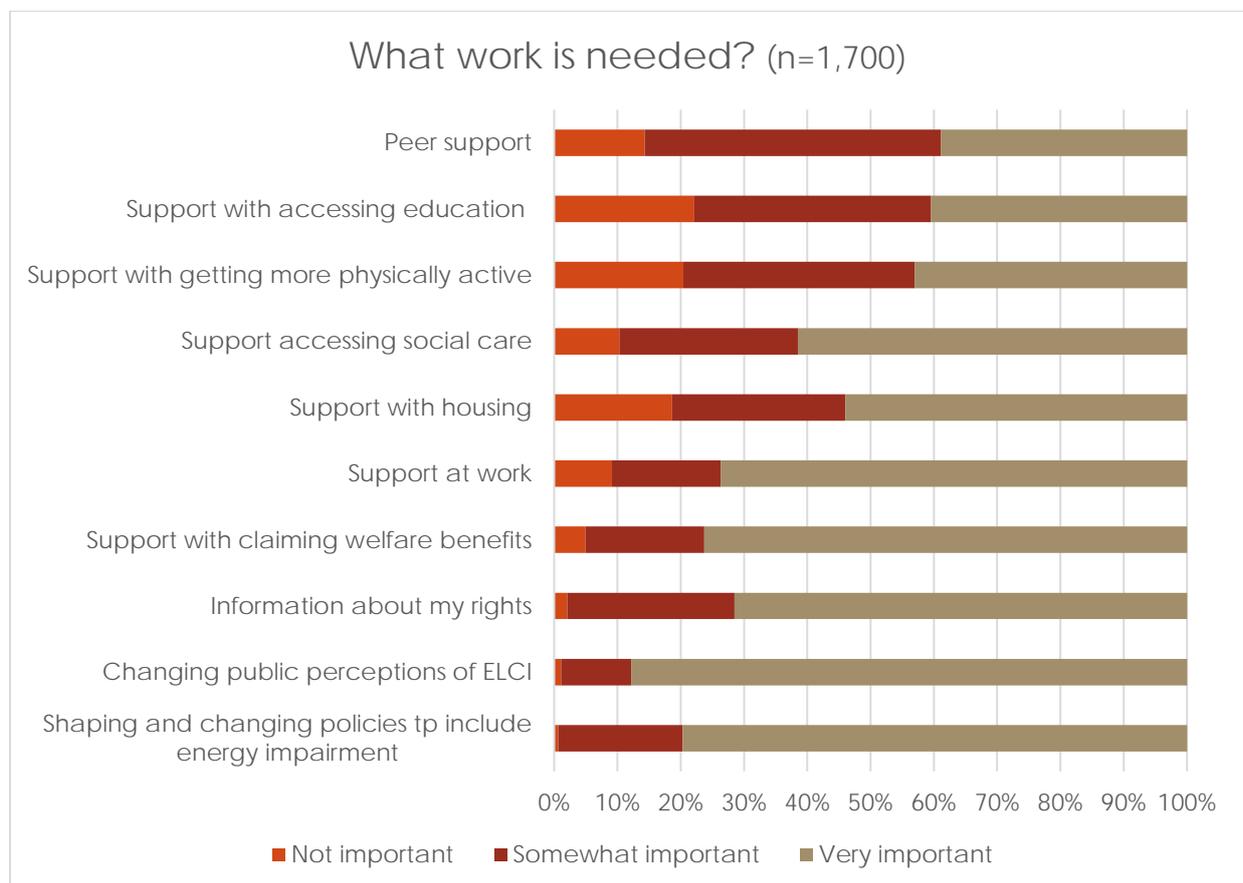
Many respondents noted that statutory care and support was almost impossible to access, despite being greatly needed: *"I can't care for myself any more and don't know how to access help"; "I can't keep my house clean due to my limitations and it affects my mental health"*.



Some respondents called for innovative schemes of flexible support to adapt to their fluctuating condition, for example: *"A company ... to help with chores like some house work or shopping or lifts to appointments, that you can just call on your bad days and they'll have a person that can help."*

Involving people with ELCs in shaping a plan for change

We asked: *Which of the following activities and services would improve your wellbeing and participation in society?* Answer options were “very important”; “somewhat important” and “not important”.



Unsurprisingly, given the predominance of awareness raising education around ELCs as solutions, respondents’ highest priorities for improving the life chances of people with ELCs were ‘changing public perceptions’ and ‘shaping and changing policies to include ELCs’.

However, between a half and three-quarters of respondents also thought that support with claiming welfare benefits, housing, social care, workplace support and accessing information about their rights was very important.

Fewer than half thought that support with education, accessing peer support or getting more physically active was very important. Possible explanations for this include 1) Our sample of respondents may have been weighted towards the over 25 age range and not in full time education. 2) Peer support communities are flourishing and vibrant within the social media networks

through which our respondents were recruited. 3) Increasing physical activity can be harmful to health for some ELCs such as ME/CFS and Long Covid.

TABLE 3: ACTIVITIES FOR CHANGE, IN ORDER OF IMPORTANCE

	Very important
Changing public perceptions of ELCs	87.98%
Shaping and changing policies to include energy impairment	80.00%
Support with claiming welfare benefits	76.45%
Support at work	74.10%
Information about my rights	71.82%
Support accessing social care	61.65%
Support with housing	54.31%
Support with getting more physically active	43.26%
Support with accessing education	40.65%
Peer support	39.18%

Involving people with ELCs in creating change

We asked: ***Would you be interested in being part of a panel of ‘experts by experience’ to help raise awareness and improve provisions for energy-limiting conditions?*** The answer options were “Yes”, “No” and “maybe”.

Around three-quarters of all respondents, (1,282 people), replied either “yes” or “maybe” when asked if they wanted to share their expertise and be part of the change needed to improve the lives of people with ELCs.

Overall, 34% said “yes”; 25% said “no” and 42% said “maybe”.

Moreover, over 1,000 respondents volunteered their contact details to hear directly about any involvement opportunities.

This is a demonstration of the strength of feeling among people with ELCs and their desire to have a voice in decisions that affect them and play their part in creating change.

Conclusions

The high volume of responses to our survey provides us with a mandate, as well as a roadmap, for social justice and change directly from people living with ELCs themselves. More than half of our 1,700 respondents wanted to be actively involved in this change.

Our survey demonstrates that, like other disabled people, those with ELCs encounter socially constructed barriers to wellbeing and participation in society. Our findings show that many of the barriers are unique to this group. They equally offer us concrete solutions and convey the urgent need to act.

The greatest barrier to equality and inclusion named by our respondents is lack of understanding of ELCs as a type of disability. Second is the invalidation and disbelief that so often accompanies this ignorance.

It comes as no surprise then that, among the solutions demanded by people with ELCs, improved awareness and understanding of the lived experience of ELCs **as a type of disability** was by far the most common theme. Respondents called above all for a programme of education about ELCs aimed at employers, disability benefit assessors and decision makers and policy actors. Another key group mentioned in relation to education was healthcare professionals. The stigma of disbelief and the dismissal of lived experience was too often traced back to the medical approach to ELCs. Healthcare staff need much better training in supporting patients with complex, debilitating and often poorly understood conditions to live as well as possible.

Environmental and other barriers to access and participation also need addressing. Many of the solutions are relatively simple, including more seating, less ambient noise, easier access to Blue Badge scheme, for example. Employment opportunities for people with ELCs can also be increased by relatively simple flexible working solutions such as remote working. The Covid19 lockdowns showed us how easily this can be done when the collective will is there.

To implement these solutions, we need to radically reframe the perception of ELCs throughout society. Until it is seen and understood as a type of disability, the effective adjustments and accommodations needed for greater access and inclusion will remain off the disability inclusion menu.

Respondents called for much better systems in place to provide income security to those who cannot work full time, and support with daily living to empower them to contribute to society. These measures are crucial to ensure talent and potential are not lost to the brutal battle for day-to-day survival

that traps so many lives. Disability assessment systems must be redesigned to capture the lived experience of impairment. Disability policy making and service planning must include the ELC impairment group as a major constituency.

The structural injustices facing people with Long Covid are the same as for fibromyalgia, lupus, ME/CFS and many more ELCs. But people with ELCs lag behind other impairment groups, such as the Deaf community and the movement for neurodiversity, within the Disabled People's Movement for liberation. The medical model of chronic illness, which privileges diagnostic categories over lived experience must be, in part, to blame.

The medical model classifies people according to diagnosis and institutionalises the dismissal and disbelief of impairment experiences that cannot be explained by science. This disbelief is often internalised. It hinders disability identity and it erases the common ground that unites us.

The tragic emergence of Long Covid is an enduring legacy of the pandemic. It must be a catalyst for change at this crucial moment in our nation's recovery. We must now act together, with stakeholders from various ELC communities alongside disability rights experts, to strengthen and deliver rights and support for people with energy limiting conditions so they are not left behind.

Recommendations

Removing societal barriers for disabled people with ELCs requires action on many levels of society, and across several government departments. Here we present the most pressing areas of change emerging from our survey respondents, organised by department. Further research and consultation with people with ELCs are needed to develop more detailed proposals for policy change.

The Disability Unit should:

- Ensure ELCs are included in government monitoring of disability. This entails standardising the category of 'impairment of stamina, breathing or fatigue', which is recommended by the Office for National Statistics, across all social research, and developing the terminology to align with the self-identity of people with this impairment type
- Engage with lived experience organisations for people with ELCs such as Chronic Illness Inclusion
- Develop awareness campaigns to improve public attitudes to ELCs alongside other invisible disabilities.

The Department for Work and Pensions should:

- Take account of the lived experience of ELCs when revising or redesigning descriptors and criteria for disability assessments
- Provide training for assessors and decision makers on the impact of ELCs on work and daily living activities
- Improve income security and financial support for disabled people who are unable to work, or need to work part-time due to an ELC
- Commission specialist employment support for ELCs
- Train frontline Jobcentre Plus advisers to understand work limitations and respond appropriately to clients with ELCs

The Department for Transport should:

- Plan for greater accessibility of public transport and public spaces for people with ELCs by increasing the provision of seating, public toilets and disabled parking bays, in consultation with people with ELCs
- Reform the process and eligibility criteria for the Blue badge scheme to make it more accessible to people with ELCs

The Department for Health and Social Care should:

- Provide training for health and social care professionals on the lived experience of ELCs, led by experts by experience

- Involve people with ELCs in the development and evaluation of services for patients with poorly understood conditions, sometimes known as Medically Unexplained Symptoms, as well as disease-specific services

The Department for Business, Energy and Industrial Strategy should:

- Promote the needs of disabled workers with ELCs within its strategy for building a more diverse workforce and a stronger economy.

Report by Catherine Hale, Director, Chronic Illness Inclusion.

Appendix

Key themes and sub-themes in order of frequency

	Frequency
<p>Raise awareness; improve understanding; educate professionals and the public about ELCs</p> <p><i>Sub-themes: invisible illness; hidden impairment; fatigue; fluctuation; living with chronic illness; need for pacing, cognitive dysfunction.</i></p>	191
<p><i>Linked theme: Being believed; listened to and taken seriously</i></p>	55
<p>Improve access to public spaces and events</p> <p><i>Sub-themes: More seating in public places; quiet areas for resting; wheelchair accessible transport and venues; more public toilets; easier access to Blue Badge scheme; more disabled parking bays. Reduce music in shops; reduce queuing. Better provision of mobility aids and equipment. Change attitudes to invisible disability.</i></p>	119
<p><i>Linked theme: online access to events</i></p>	19
<p>Improve healthcare services</p> <p><i>Educate healthcare professionals about the impact of ELCs; more specialist training and services; faster diagnosis; better care coordination; access to alternative therapies; respect and listen to patients; more telehealthcare.</i></p>	111
<p><i>Linked theme: better mental health support</i></p>	10
<p>Increase employment opportunities</p> <p><i>More flexible working opportunities; more home working opportunities; improve understanding of ELCs among employers and HR; reform Sick Leave policies and processes; improve Occupational Health support</i></p>	110
<p>Improve income security and benefits system</p> <p><i>Reduce the burden of claiming benefits; increase the level of benefits; financially support people for working part-time; improve the understanding of ELCs in assessments</i></p>	105
<p><i>Linked theme: challenge attitudes and stigma from DWP</i></p>	29
<p>Increase support and assistance with daily living</p>	61