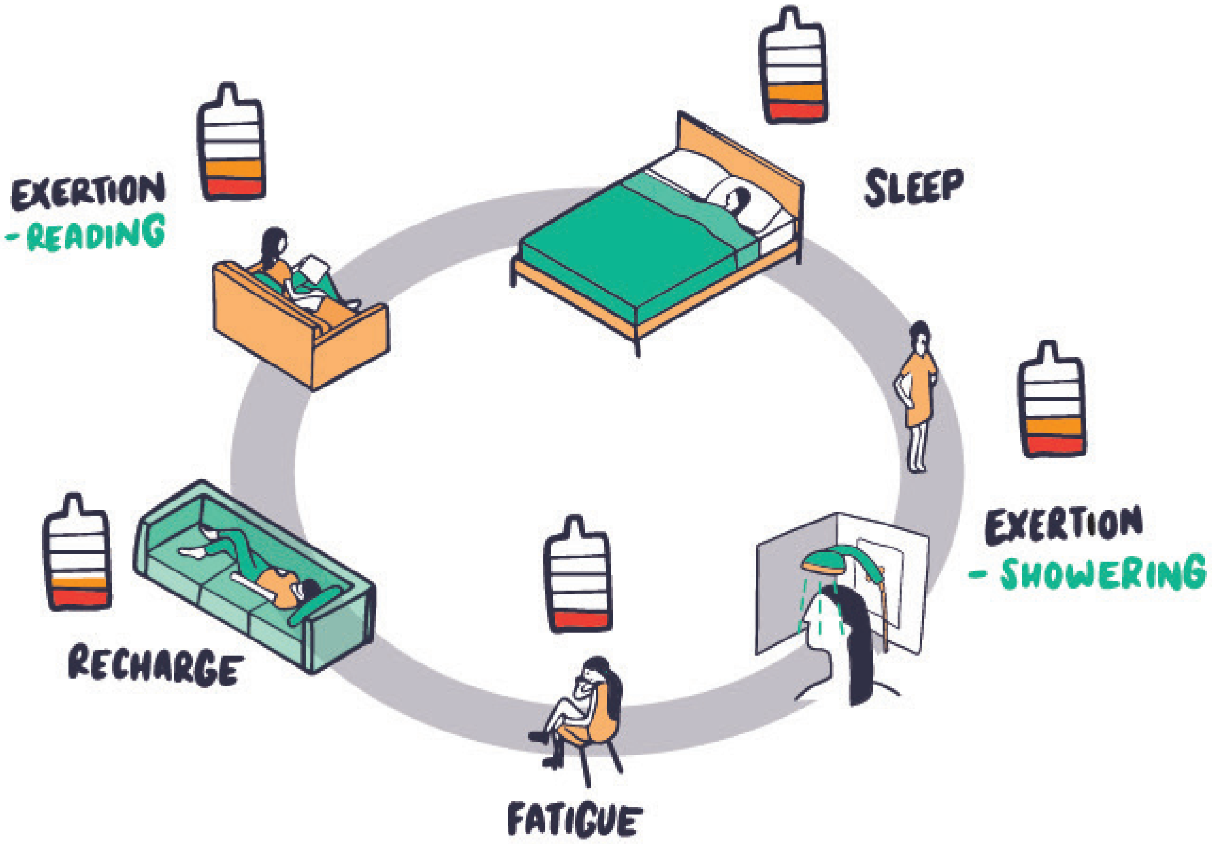
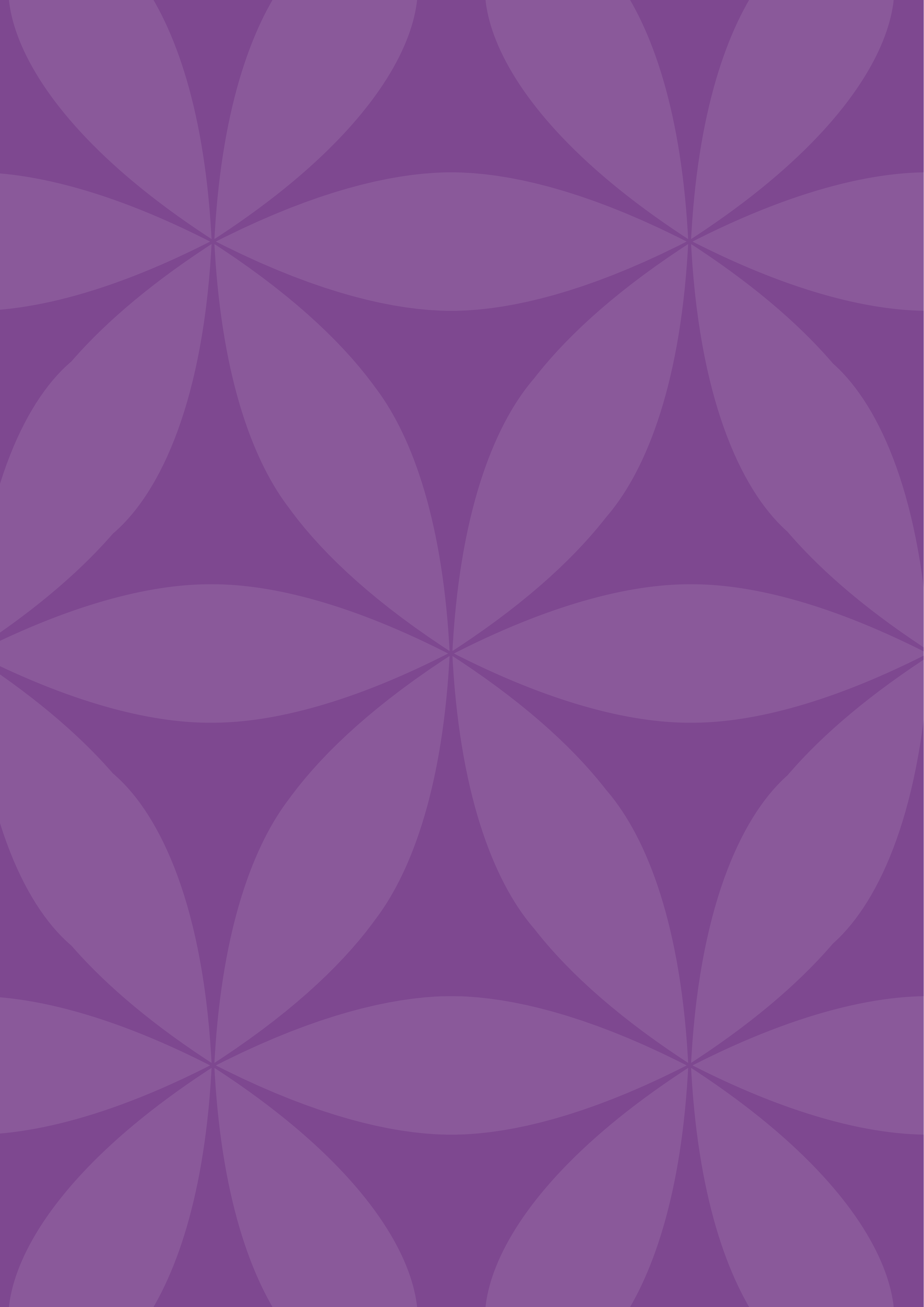
“I already have a job… getting through the day”

ENERGY LIMITING CHRONIC ILLNESS (ELCI), SOCIAL INCLUSION, EMPLOYMENT AND SOCIAL SECURITY

by **Catherine Hale, Stef Benstead, Dr Kate Hardy and Dr Jo Ingold**





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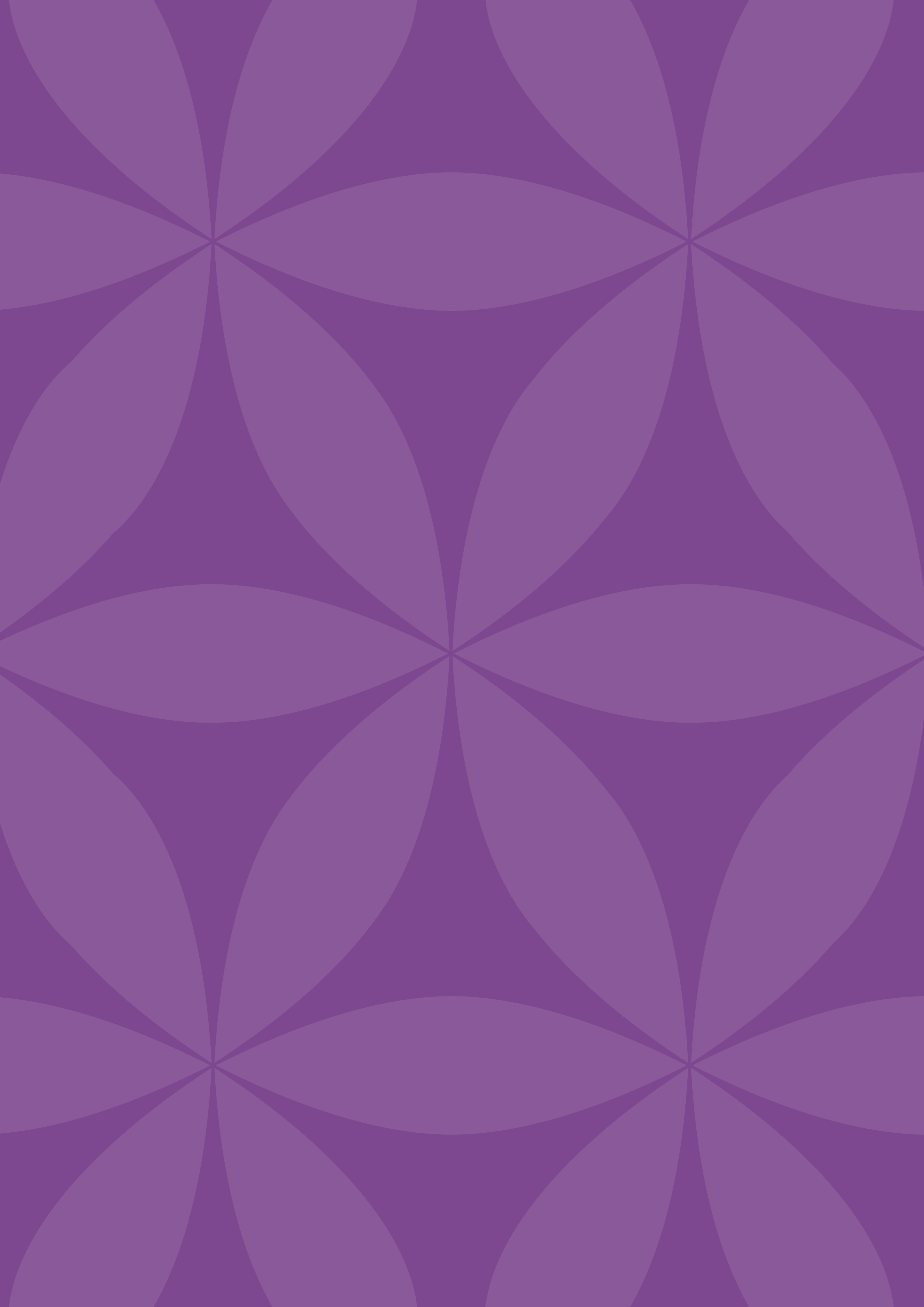


FOREWORD

"This report provides a compelling case for why we need to think about energy limiting chronic illness (ELCI) separately to other impairments/ disabilities. It is based upon the lived experience of ELCI, brought together with the authors' considerable expertise in social security and employment policy into a clear and convincing message. It is essential reading for anyone connected to the world of work, to disability support/policy, to healthcare, to social security, or to anyone who knows someone with an ELCI – in other words, it is essential reading for pretty much everyone."

Dr Ben Geiger, Senior Lecturer in Social Policy, University of Kent and co-lead of the Welfare at a Social Distance project

"This is a ground-breaking and unique piece of research by the Chronic Illness Inclusion Project. Unique because this research was led by those with energy limiting chronic illnesses themselves. Ground-breaking because the research not only challenges the assumptions that underpin current social security and employability policy but holes the entire system below the waterline. Simply put, the current Work Capability Assessment system and the job coaching on offer via the DWP are failing as many as a third of disabled people who have energy limiting chronic illnesses.

"It's not only policy-makers but disabled people's organisations themselves that have to recognise that this impairment group exists and has particular needs that must be met before they can be involved in the inclusive living movement. DPOs and policy-makers could find no better place to start learning about those needs than through this research."

Bill Scott, Senior Policy Adviser to Inclusion Scotland, Chair of the Poverty and Inequality Commission for Scotland

EXECUTIVE SUMMARY

This report presents the findings and recommendations from a study into social inclusion, employment and social security for disabled people with energy limiting chronic illness (ELCI). The study forms part of the Chronic Illness Inclusion Project (CIIP), a participatory research project by, and with, the chronic illness community in the UK. The first phase of research focused on chronic illness and disability identity, including a survey of over 2,000 disabled people. This report focuses on the second phase of research, involving in-depth discussion of participants' experiences of employment and social security.

Main Findings

- People with energy limiting chronic illness form a discrete sub-group of disabled people.
- Work can be bad for health with ELCI. Energy impairment affects the amount, rather than the type, of activity people can do and aids and adjustments cannot fully mitigate its impact.
- In the workplace, inflexible, performance-based and rigid human resource policies and practices are a barrier to employment and a lack of autonomy and control risks exacerbating illness.
- There is a need for job carving and job brokering agencies, such as Astriid, who can maximise opportunities for people with ELCI by working with employers to specifically create suitable jobs.
- For social security, disability assessments fail to account for energy impairment, especially its key features of payback, reduced capacity and cognitive dysfunction.
- This report may be timely in addressing the circumstances of those newly experiencing 'Long Covid', which appears to impact approximately 2% of people who remain ill with Covid after three months.

ELCI and Work

One in three disabled people of working age in the UK experiences impairment of stamina, breathing or fatigue. This is the current closest match to the concept of ELCI. Despite the size of this group, employment and social security policies and systems have not considered or been designed for the particular needs of this group of people. This report outlines some of the failings of these systems and policies and underscores the importance of taking account of the lived experiences of people with ELCI to improve provision in the future.

People with chronic physical illness experience a diverse and wide-ranging set of symptoms, which impact on their daily lives and, importantly, their ability to work. Until now, policy makers have identified this group through various categories of medical diagnosis, or through the catch-all term 'long-term health conditions'. This report contends that **people with energy limiting chronic illness form a discrete sub-group of disabled people**. This group has remained hidden within disability-related policies because their lived experiences of illness and impairment are widely misunderstood and often discredited, denied and disbelieved. The consequence of this is **disability assessments that fail to account for impairment with chronic illness**; a social security system that is disabling rather than enabling; and a lack of appropriate support and adjustments in employment.

The majority of our participants had previously had employment in high-skilled professional roles but were now largely not engaged in paid work. When asked about social inclusion, our participants reported that having a sense of meaning or purpose in life was very important to them, as was social connectedness. The meaning of social inclusion for our participants centred on these factors. Paid work was not the only route, and typically was not the best or even a viable route, to social inclusion.

People with ELCI are excluded from employment by a complex interaction of impairment or health with social, structural, and systemic barriers. From our research, **the primary limitation for participants with ELCI was the amount, not the type, of work, and the unpredictability of work capability from day to day**. Some had no, or few, productive hours of energy left after essential activities of daily living such as washing and dressing. These limitations are much less easily mitigated by aids and adaptation, or typical adjustments to the work environment; there are no aids that give someone more energy. More critical to the inclusion of people with ELCI in the labour market are adjustments such as reductions in working hours, working from home, flexibility over hours and high autonomy.

Work itself can be disabling. For many people with ELCI, work simply isn't possible. But for those with some capacity for work, the nature of work can be disabling – performance-based and rigid human resource policies/practices are barriers remove autonomy, which risks exacerbating illness. Lack of understanding of ELCI as a type of disability also creates unnecessary barriers to disability disclosure and the provision of necessary adjustments.

Information and training about ELCI for employers, recruitment managers and line managers is key to increasing employment opportunities. In contrast to other impairment groups, employment support intermediaries to specifically broker job opportunities for people with ELCI are almost non-existent, except for Astriid. This means that employers are not informed or incentivised to create job opportunities that maximise the opportunities for people with ELCI. There is a need for developing and resourcing organisations like Astriid who work to maximise opportunities for people with ELCI by working with employers to specifically create suitable jobs.

Social Security

Employment policy and social security policy must be properly joined up in order to improve the lives of people with ELCI. A robust social security system is key to ensuring social inclusion and participation for people with ELCI who have no or very few hours in which they are able to work, as well as those who can work part-time and can't earn enough to support themselves.

As the gateway to social security entitlement and employment support, the Work Capability Assessment (WCA) was a key feature of life for our participants. However, their experiences demonstrated that **WCAs fail to account for energy limiting chronic illness, especially its key features of energy impairment, payback, reduced capacity, cognitive dysfunction and diverse illness symptoms**. WCAs also fail to measure the key indicator of employability for this group, which is the number and predictability of productive hours. This results in incorrect decisions, disentitlement to support and a distressing appeals process. The overall system results in a deterioration in health and a pervasive sense of insecurity that undermines health and pathways into employment.

The WCA is based on a flawed and discredited model of 'disability assessment medicine' (DAM) that dismisses ELCI as a form of impairment and instead attributes incapacity for work to personal failings. DAM construes the lived experience and testimony of people with ELCI as contentious, perpetuating misunderstanding and myths surrounding the impairment and its symptoms. The experiences of our participants demonstrate that this results in a social security system that is a hostile environment based on adversarial relations for people with energy impairment. The division into 'severely disabled' or 'just common health problems' does not reflect the reality of lived experiences of people with ELCI, which is of chronic illness beyond the scope of 'common health problems' and frequently in the 'severe' range.

The culture of disbelief which has characterised attitudes to ELCI means that **people with ELCI live in constant fear of suspicion, judgement and hostility from the public, as well as from benefit assessors and even medical professionals**. The fear of being seen engaging in activity, and reported to the DWP or mis-assessed for benefits, is a key barrier to social inclusion reported by participants. Anxiety and insecurity arising from this undoubtedly results in people with ELCI being further away from work, rather than closer to it.

The Context of Covid-19

Although the research informing this report pre-dates the Covid-19 pandemic in 2020, there is evidence that approximately 10% have at least one symptom for three weeks and 2% of those infected by the virus remain symptomatic after three months. This condition has become known as 'Long Covid'. Fatigue, post-exertional malaise and cognitive dysfunction are reported as the most prevalent symptom of 'Long Covid', with nearly half of patients having to reduce work as a result. 'Long Covid' may emerge as another form of ELCI, resulting in a new cohort of disabled people unable to remain in full-time employment and facing income insecurity. This report is therefore timely in addressing their circumstances.

It is also timely in addressing the kinds of flexible working practices required by people with ELCI to promote employment. Remote working, facilitated by video conferencing technology, swiftly became the norm at the start of the Covid-19 pandemic. The culture change that this shift entailed must be harnessed into strategies for Equality, Diversity and Inclusion into the future.

This report is long overdue in revealing the extent of exclusion of people with ELCI from wider society and, where possible for them, paid work. This group has for too long remained hidden. The time has come to listen to the lived experience of people with ELCI and to formulate policies and services that respond to their needs, in order to empower them to participate in society and avoid further lost talent.

INTRODUCTION

This report presents findings and recommendations from a study into social inclusion, employment and social security for disabled people with energy limiting chronic illness (ELCI). The study forms part of the Chronic Illness Inclusion Project (CIIP), a participatory research project by, and with, the chronic illness community in the UK. The first phase of research focused on chronic illness and disability identity, including a survey of over 2,000 disabled people.[3] This report focuses on the second phase of research, involving in-depth discussion of focus group participants' experiences of employment and social security.

The research informing this report pre-dates the coronavirus (Covid-19) pandemic in 2020. Evidence from the Covid Symptom Study suggests that 2% of those infected by the virus remain symptomatic after twelve weeks.[4] The most frequent symptoms reported in patients with 'Long Covid' for six months or more are fatigue, post-exertional malaise, and cognitive dysfunction.[5] 45% of this cohort reported having to reduce their work schedule as a result, and 22% were not able to work at all.

'Long Covid' may emerge as another form of ELCI, creating a new cohort of disabled people unable to remain in full-time employment and facing income insecurity. This report is therefore timely in addressing their circumstances and may be suggestive in how to address the work, employment and social security needs of those with 'Long Covid'.

Within the first phase of research, the CIIP developed the term ELCI, and the related concept of 'energy impairment', to convey the lived experience of chronic illness reported by participants through both qualitative and quantitative research. The concept of ELCI is most closely matched in current official measures by the Office for National Statistics category of impairment of stamina, breathing and/or fatigue. These impairments affect 1 in 3 disabled people in the UK, and it is the third most common impairment group among working age disability benefit claimants, after mobility and mental health.[6] Yet, as this report shows, ELCI is widely misunderstood.

The lived experience of ELCI stands in sharp contrast with the misunderstandings and myths about people with chronic illness that informs social security and employment policy and practice in the UK. According to the architects of 'welfare reform', chronic illnesses are 'common health problems', rather than a genuine form of impairment or disability, and the 'attitudes' and 'motivation' of people with chronic illness are too often perceived to be the main factors that keep them away from work, rather than their debilitating chronic illness.[7]

Methods

The research was conceived in the tradition of emancipatory disability research and was planned, conducted and analysed by disabled researchers living with chronic illness.[8]

The research was underpinned by the social model of disability, following three broad principles:

1. Centring disabled people's lived experience of impairment and disability
2. Prioritising their own goals and aspirations and eliciting their understandings of social citizenship/inclusion/participation
3. Identifying the societal, institutional or systemic barriers to realising their goals

An extended online research forum for 20 participants living in the UK was held in 2018 for a period of eight weeks. The participants were recruited from among members of online chronic illness communities and networks who had subscribed to the CIIP mailing list. Applicants were selected to represent a broad spectrum of chronic illness diagnoses and range of functional impairment, and as far as possible to balance age and sex.

Due to the requirement of the research, we did not include anyone who said they could not manage at least five hours of computer usage per week. Nevertheless, participants reported a range of severities from 10% (very severe) to 60% (can work full-time in light duties if hours are flexible) on the Bell Fatigue Scale.[9] Table 1 outlines the characteristics of the participants, including key demographics, medical diagnoses, employment history and status and Bell Fatigue Scale. Table 2 indicates the multiple diagnoses received by participants.

Participants were presented with a new topic and set of questions every two weeks. In order to enable the participation of people with fluctuating and energy limiting conditions, participants could answer questions and then interact with other participants at any time, and from home. This begins a process of developing research methods which are suitable for working with participants with ELCI. Data were coded and thematically analysed using Nvivo software. In all cases, the confidentiality and anonymity of individuals was protected and participants have been given pseudonyms. The wider research within which this is based includes a survey of over 2,000 disabled respondents.[10] The study was approved by the DRILL Ethics Committee.

Key to Table 1:

ESA – Employment Support Allowance

SG – Support Group (a component of ESA)

DLA – Disability Living Allowance

PIP – Personal Independence Payment

CTC – Child Tax Credit

WTC – Working Tax Credit

Bell Fatigue Scale – a fatigue rating scale for mental as well as physical fatigue developed by Dr David Bell.

Scale is scored from 0 (very severe, bedridden constantly) – 100 (healthy)

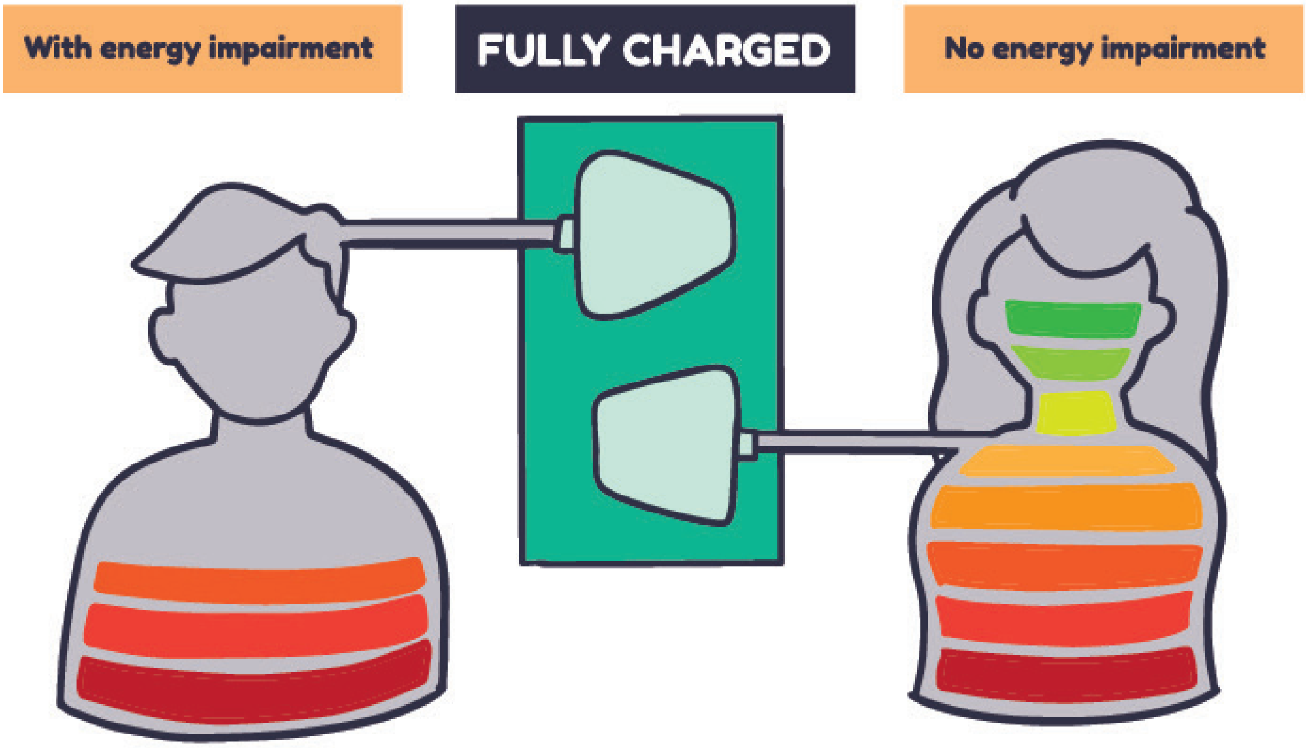
Pseudonym	First Listed Diagnosis	Previous Work	Current Work	Benefits	Age	Sex	Bell Fatigue Scale
Amanda	COPD	Teacher		DLA	40-65	F	10
Betty	Autoimmune	same as current	Hairdresser: 30 hours per week, self-employed	PIP	25-39	F	50
Charlotte	CFS/ME, Fibromyaligia	Secondary education	Data Analyst: 5 hours per week, from home	ESA, PIP	25-39	F	30
Denise	Hashimoto's Syndrome	Community & youth work		PIP	40-65	F	60
Eleanor	Grave's Disease	NHS Senior Manager		ESA, PIP	40-65	F	30
Faye	hEDS	Science graduate	PA for disabled relative, 2 hours per week	CTC, WTC as household	40-65	F	40
George	ME/CFS	Healthcare Contracts Manager		None, early retirement	40-65	M	50
Hugh	FND	Nurse, Data Analyst		ESA (SG)	40-65	M	30
Juliet	Liver Disease	Teacher		ESA	40-65	F	30
Kathy	ME, Fibromyaligia	Teacher		ESA	25-39	F	30
Lydia	Gastric issues	Not available			18-24	F	50
Michael	Refractive Sarcoidosis	Asset Management for Local Authority		ESA	25-39	M	30
Olivia	Cystic Fibrosis		Volunteer with NHS, 2 hours per week	ESA,DLA	25-39	F	DM
Phil	Juvenile Rheumatoid Athritis	Bank Manager		PIP	40-65	M	30
Rebecca	Fibromyalgia, Osteoarthritis	Teacher	Volunteer running an online mental health support forum	PIP, Ill-health pension	25-39	F	30
Samantha	ME, Epilesy	Human Resources Officer, Full Time	Human Resources Officer, 18 hours per week		25-39	F	20
Tricia	Sicca Syndrome	Church Minister		PIP, Ill-health pension	40-65	F	20

TABLE 1. Participant Characteristics

Pseudonym	Diagnoses
Amanda	Chronic obstructive pulmonary disease, depression, pulmonary hypertension
Betty	Autoimmune, Ankylosing Spondylitis, hypermobility Ehlers-Danlos Syndrome, postural tachycardia. MBL deficiency, fibro, migraines/cluster headaches, pulmonary stenosis, endometriosis, prolapse disc's and nerve root impingement
Charlotte	Chronic Fatigue Syndrome/ME, Fibromyalgia, partial deafness, hypermobility, hypertension, depression
Denise	Hashimoto's Syndrome, polycystic ovary syndrome, hypermobility syndrome with joint instability
Eleanor	Graves disease, leading to anxiety, panic attacks, agoraphobia, severe weight loss, muscle wastage and weakness, palpitations (PVCs and bigeminal runs) brain fog, unexplained rages
Faye	hypermobility Ehlers-Danlos Syndrome
George	ME/Chronic Fatigue Syndrome, cancer
Hugh	Functional Neurological Disorder
Juliet	Stage 4 liver disease, rheumatoid arthritis, osteoporosis, irritable bowel, multiple allergies, asthma, joint pains, nausea, vomiting, insomnia, ascites, oesophageal varices, loss of appetite and fatigue. mild hepatic encephalopathy
Kathy	Diabetes type 2, ME, Fibromyalgia, anxiety, panic attacks, dyspraxia, migraines
Lydia	Gastric issues, possibly related to Small Intestinal Bacterial Overgrowth or mild gastroparesis. Food intolerance leads to weight loss, fatigue, pain
Michael	Refractive Sarcoidosis, depression
Olivia	Cystic Fibrosis, Diabetes
Phil	Juvenile Rheumatoid Athritis, deformities, Osteoarthritis, Generalised Anxiety Disorder, Obsessive compulsive disorder (Pure O)
Rebecca	Fibromyalgia, Osteoarthritis, Scoliosis, degenerative disc disease, pernicious anaemia, chronic fatigue syndrome, brain fog, hemicrania migraine
Samantha	Severe ME with orthostatic intolerance, epilepsy, severe menstrual problems
Tricia	Sicca Syndrome/Sjogren's Syndrome

TABLE 2. Diagnoses Reported by Participants

Energy Impairment



1. About Energy Limiting Chronic Illness (ELCI)

People with chronic physical illness experience a diverse and wide-ranging set of symptoms, which impact on their daily lives and, importantly, their ability to work. Until now, policy makers have identified this group through various categories of medical diagnosis, or through the catch-all term 'long term health conditions'. But there is strong evidence that, for many people, the impact of chronic illness on day-to-day life is shared across a broad range of diseases. We can, therefore, speak of **chronic illness as creating a type of impairment, equivalent to mobility impairment, sensory impairment or neurodiversity**.

This report contends that **people with energy limiting chronic illness form a discrete sub-group of disabled people**. This group has remained hidden within disability-related policies because their lived experiences of illness and impairment are widely misunderstood and often discredited, denied and disbelieved. The consequences of this are that disability assessments fail to account for impairment due to chronic illness; social security is disabling rather than enabling; and there is a lack of appropriate employment support.

What is energy limiting chronic illness?

Energy limiting chronic illness (ELCI) is a new term, born out of the participatory research by and with people with physical chronic illness reported here. The new concept of ELCI reflects the findings of this research, namely that:

1. Fatigue and energy limitation were rated as the most restrictive feature of chronic illness for a broad range of participants; and
2. The existing lexicon of impairment and disability, in particular the term 'fatigue', does not adequately convey the lived experience of chronic illness, and new terminology is needed.

ELCI is a debilitating mix of physical fatigue, cognitive fatigue and pain alongside other diverse illness symptoms. The impact of ELCI on everyday life and work cannot be conveyed by describing symptoms in isolation. It requires a concept that conveys the global impact of chronic illness. The CIIP proposes the concept of 'energy impairment' to convey this experience.

The concepts of ELCI and energy impairment challenge us to think differently about disability. Cultural stereotypes of disability involve fixed and visible differences; binary understandings of 'can' and 'can't' in relation to tasks and activities. For people with ELCI this is not the reality. The ability to do an activity depends more on what has been done before it, what needs to be done after it, fluctuation in symptoms, and environmental stressors than on any fixed impairment. Typically many bodily systems and functions are affected. The overall impact of ELCI can be severely debilitating and render people unable to work at all.

This chapter describes the lived experience of energy impairment, as told by our participants, and its key features in relation to employment and social security. These features include payback, fluctuation and cognitive dysfunction, as well as individual symptom effects.

Who has ELCI?

According to government research, one in three disabled people of working age in the UK experiences impairment of stamina, breathing or fatigue (SBF).[11] This correlates with data on ESA claimants from the 2020 Welfare at a Social Distance project showing that 41% reported impairment of SBF.[12] SBF is not exactly the same as ELCI or EI, but it is the closest measure we currently have. Many people with SBF impairment are likely to have ELCI; and many people with ELCI are likely to experience SBF impairment. However, the two are not synonymous and should not be taken as such.

ELCI covers a wide range of physical health conditions. Among WHO disease categories, the most represented are neurological and musculoskeletal diseases, followed by endocrinological, respiratory, digestive system and circulatory diseases. Most people have multiple health conditions, with respondents to our survey reporting an average of 3.5 conditions each. 46% per cent of our respondents who said they have SBF impairment also reported a comorbid mental health condition.

ELCI is often an invisible impairment: 9 out of 10 survey respondents said their impairment was not normally visible to others.

In our survey, over 90% of people who said that they would use the term ELCI were female (compared to 84% of all respondents). This does not mean that a person has to be female to have ELCI, but may mean that the conditions most likely to result in ELCI are more common in women. This is of particular interest because the cardiovascular conditions that underlie the medical understanding of SBF impairment are more common among men.

Condition	All Respondents
Post-viral fatigue syndrome	670
Fibromyalgia	517
Asthma	180
Other Arthritis	170
Osteoarthritis	133
IBS	131
Arrhythmias	118
Migraines	107
Low Thyroid	101
Chronic Fatigue Syndrome	81
Rheumatism	75
Inflammatory Bowel Disease	73
Autonomic	71
Pain	68
Sleep	62
MS	62
Sensory	62
COPD	56
Osteoporosis	40
Hypertension	40
Infectious disease	39
Raynaud's	37
GERD	36
Heart disease	35
Mononeuropathy	34
Diabetes	33
Psoriasis	32
Cancer	30
Ovarian problems	30
MCAS	28
Guillain Barre	24

TABLE 3. Conditions shown are those reported by at least 30 survey respondents reporting at least one physical health condition. N=1851

Key features of ELCI

The global impact of ELCI on daily living and work can be explained through its key features. These are energy impairment, fluctuation, payback, cognitive dysfunction and illness symptoms. Below is how our participants described each of these.

Energy impairment

Almost all participants conveyed the idea of having a drastically limited supply of energy, which gets exhausted through simple tasks of daily living that non-disabled people take for granted. All tasks, whether physical or mental, draw upon this limited supply, and physical tasks drain capacity for cognitive tasks, and vice versa. Once capacity is used up, any further task or activity become impossible or can only be performed at risk to the safety of one's self or others, or at high health cost over ensuing days and even weeks. The concept of limited capacity for activity is known colloquially as 'spoon theory,' in which 'spoons' are a metaphor for units of energy or healthy capacity.[13] Michael describes how it is the totality of energy impairment, rather than the individual symptoms of his lung disease, that restrict him:

> *The stiff joints, the blurred vision, the headaches, nausea and vertigo, all of that I can tolerate but it's the fatigue that keeps me housebound and out of work. No matter how much rest I get or how hard I will myself to try, I simply have no energy. When even the simplest tasks are monumental challenges that leave you drained, how are you supposed to live?*
> Michael

Participants often contrasted the common perception of '**fatigue**' (heavy or extreme tiredness) with the lived experience of ELCI, in which 'fatigue' is a debilitating, all-encompassing level of physical and cognitive fatigue that is disproportionate to the level of activity. Participants in our first focus group described this 'fatigue' as "wading in cement", "a heavy aching feeling that makes it hard to move your body at all"; "severe, constant, body/mind consuming"; "brutal"; "life-destroying"; "a bone deep, spaced-out exhaustion" and "so tired you feel drunk".

> *This is more than exhaustion, it's more than fatigue it's deeper and harder to get through and has ladles of guilt attached.*
> Rebecca

> *Fatigue is such a gentle word and a million miles from what I feel right now.*
> Amanda

With energy impairment, function is only restored through prolonged, pronounced and disproportionate refraining from activity, which is not adequately captured by common experiences of 'rest'.

Energy impairment is the main feature of ELCI, but it may also be experienced by people with other impairments or health conditions as a secondary feature.

Payback

Payback helps to distinguish the experience of ELCI from simple fatigue and is a key part of what makes ELCI so debilitating. The notion of payback is used to describe both an aggravation of symptoms, and a reduction in overall energy available, following over-exertion. Worsened symptoms typically include physical fatigue, cognitive fatigue, pain, and other illness symptoms depending upon the specific illness(es) experienced by the individual (see Table 3). With some health conditions this is referred to medically as 'post-exertional malaise'.

Depending on the illness, the individual and the degree of over-exertion, payback can occur soon after over-exertion, or one or two days after. It may be alleviated by immediate rest, or it may last for several days or even weeks. This exacerbation of illness symptoms is disproportionate to the activity involved, and continues to get worse if activity levels are not reduced.

Payback is one of the reasons that abilities and capacities with ELCI are not static and fixed, but determined by how a person's limited energy supply has already been used or allocated within a day or week.

> *Every task from "basic" personal care to filling in forms, dealing with people, housework etc takes energy and for each event there are days' worth of payback where I'm not able to do very much at all.*
> Rebecca

Fluctuation

On top of the dynamics of energy use and payback, many participants reported a variability in symptoms and functional levels that was inherent to their condition, rather than resulting from over-exertion. Fluctuation is the variability of symptoms over days, weeks, or months. It leads to unpredictable levels of energy. Fluctuation is a feature of most ELCIs due to their systemic nature. For "Long Covid", the unpredictability of symptoms has already been widely reported.[14] A fluctuating condition affects employability even without energy impairment.

> *I can never guarantee that I'm going to be ok at a particular time on a particular day. I can increase the chances with careful management, but I can't guarantee it.*
> Charlotte

> *You can feel fine in the morning and be back in bed by lunchtime.*
> George

Cognitive dysfunction

Cognitive difficulties are often referred to as 'brain fog'. This term describes issues such as clouded thinking; not being able to find words or formulate sentences; not understanding spoken or written words and sentences; not being able to count or do simple maths; slowness in processing (sensory and spoken) information; balance problems and clumsiness; memory problems; a feeling of 'losing time'; inability to plan ahead (for example to do cooking); and confusing reality with memories of dreams. It was described by participants in our first forum as like having one's head "stuffed to bursting with cotton wool" or "a tiny part of my mind that still sort of functions surrounded by cotton wool in a dead body."

> *Brain fog means I don't have the cognitive abilities I used to and can't work at the level that corresponds to my education.*
>
> Faye

In addition, cognitive difficulties are often a manifestation of fatigue and energy impairment. Even if cognitive function is normal at baseline, it can very quickly decline following activity. Amanda and Tricia explain the relationship between fatigue and cognitive dysfunction:

> *Once tiredness starts, I can't do basic tasks such as counting (money), making decisions, etc. I won't drive at all because my driving becomes erratic. I make bad decisions, I'm blunt, clumsy.*
>
> Amanda

> *I know that when my fatigue is coming I get clumsy, can't think of words and my spatial awareness is worse. If I try and push through I become very light headed and even more of a danger to myself and others.*
>
> Tricia

People with ELCI usually do not meet thresholds of cognitive impairment required for diagnoses such as dementia, brain injury or learning disability. However, because cognitive difficulties are often tied to stamina and overall energy impairment, a person who starts off with 'normal' cognitive function can become unable to function after activity, and cognitive function is rapidly drained by activities required for work such as communicating, reading, driving, and planning and completing tasks (see Table 3 for further detail of cognitive difficulties). Cognitive difficulties with ELCI must be accounted for in the design of disability assessments and employment support.

Diverse illness symptoms

Physical and cognitive fatigue, energy impairment, payback and fluctuation are inherent to most forms of ELCI. But each person also experiences their own suite of symptoms based on their specific illness(es). Additional limits on function therefore also come from the specific symptoms that any given person experiences. Some examples of symptoms, the impact they have on the person and the impact they have on capacity and capability for work are given in Table 3.

The range, severity and compounding dimension of ELCI symptoms is illustrated by this quote from Amanda:

> *It feels like my brain is blistered. I have a crushing headache, my TEETH hurt, there's a pain above my eyebrows. My cheekbones ache, my back aches. If I were to stand up, my leg bones would physically hurt. I wouldn't be able to work anything out right now - simple equations or decisions. And it's only half an hour since I became 'fatigued'.*
>
> Amanda

Symptom	Effect of Symptoms	Impact on Work Capability
Physical fatigue	Difficulty walking Difficulty lifting and carrying Difficulty sitting upright Need for sleep Takes longer to do things	Difficulty remaining at a work station Time limit on capacity for work Need for prolonged rest in between bouts of work Need longer to do work
Cognitive dysfunction	Short term memory problems Difficulty finding words Difficulty with concentration Reduced awareness of surroundings Reduced response times Feelings of sleep deprivation	Difficulty conversing, reading and writing Difficulty counting and other mathematical problems Difficulty following instructions Difficulty completing a task Difficulty with making decision Make more mistakes in work, or do work to a lower quality At risk of danger to self and others Not safe to drive Clumsy and unbalanced
Pain	May be made worse by not moving, moving too much	Difficulty remaining seated for a prolonged period without movement Difficulty standing for prolonged periods Limited capacity for manual work Negative impact on concentration and cognitive function
Sleep disorder	Insomnia Excessive daytime sleepiness	Reduced capacity for work due to need for sleep during the day Need for sleep breaks in between bouts of work Reduced cognitive function
Orthostatic intolerance	Difficulties with being in upright position Exacerbated symptoms from being upright	Reduced capacity for work due to need to lie down Prolonged rest breaks needed in order to lie down
Respiratory symptoms	Physical fatigue Cognitive fatigue Reduced stamina	Reduced capacity for manual work Reduced capacity for cognitive work
Joint instability	Reduced mobility	Difficulty with manual tasks
Sensory sensitivity including multiple chemical sensitivity	Intolerance to light, especially fluorescent lighting Intolerance to noise, especially background noise Intolerance of chemicals Sensitivity to touch Poor temperature control	The need to tightly control the working environment may make office-based work inviable, eg. temperature, lighting level and type, noise level, use of cleaning and air-freshening chemicals Unable to wear work uniforms due to touch sensitivity Sensory sensitivity can make travel more fatiguing, impacting on the ability to work away from home Impact on concentration and therefore quality of work. Chemicals can trigger other symptoms

Symptom	Effect of Symptoms	Impact on Work Capability
Gastrointestinal	Bowel and bladder function Continence Nausea, vomiting Weight loss	Time needed to manage bowel or bladder continence issues Need for closeness to toilet restricts which workplaces are viable Scheduling life around toilet Limited diet can lead to weight loss and physical fatigue
Fluctuation	Variation in symptoms Symptoms may not vary in sync	Unpredictable capacity for work Difficulty meeting deadlines Risk of harm to health through over-work or working during worsened symptoms
Side effects from pain medications	Drowsiness, lethargy, brain fog	Cognitive dysfunction
Mental health comorbidity	Anxiety, depression from dealing with uncertainty and not being able to meet wellbeing needs	Reduced concentration Cognitive dysfunction

TABLE 3. Reported Symtoms and Impact on Work Capability

Daily living with ELCI

> *Once one becomes chronically ill, everything has to be controlled in a completely different way.*
>
> Phil

The dynamics of energy impairment and payback means that capacity for activity with ELCI is not fixed or categorical, but rather is determined by how limited energy has been used or allocated in daily life, as well as by the inherently fluctuating pattern of many systemic diseases. This means that it is not simply the case that people with ELCI can either perform a task or not perform it. Instead, whether people can perform it depends on what tasks and activities have been done in the preceding hours and days, what they need to be able to do later that day or week, inherent fluctuation in their condition(s), and the impact of other stressors. People with ELCI operate with a limited supply of energy and all basic tasks draw upon that limited supply.

Rationing energy

Living with ELCI demands a strategic approach to balance various essential needs for survival. It means having to carefully ration limited energy in order to accomplish basic tasks and avoid aggravating symptoms. Whether they were 'mildly' or 'severely' energy impaired, participants frequently compared their approach to daily living with financial budgeting of scarce resources. This requires daily, and often constantly-revised, calculations of available energy and how to distribute it across activities, in a way that non-disabled people do not appreciate or understand. Often it isn't possible to fit all necessary or important activities in, and one or another area has to be let go in order for another to be done:

> *It's like spinning plates, sometimes you have to let a couple wobble for a while so you can rescue the one that's about to fall off.*
>
> Charlotte

> *[I worked] out what I have given up to enable me to take part in this forum this morning. I need a shower. I need to give my son a lift. I need to complete a drawing. The shower will go to the bottom of the pile (ie never get done) the drawing will probably be abandoned for another day too. My son will get his lift if he persists and by then it will be time for bed again.*
>
> Amanda

This is compounded by the severity of energy limitation. Tasks that are experienced by people with ELCI as taking up a whole day's capacity for activity may appear 'nothing' to people without ELCI:

> *I have taken my meds, fed the cats, made coffee for myself, let my dog out into the garden, completed some online banking and worked out what bills need to be paid over the next fortnight… For me, that's a large amount of tasks… It's nothing really, is it.*
>
> Amanda

Energy trade-offs

Our participants also noted that it was not enough to just do essential personal, health and household tasks. Humans are social animals and without social contact we become ill.[15] Nevertheless, social activity is a drain on energy like all the other activities, and other activities have to be given up to make room for social needs. The same was said for activities or hobbies that brought a sense of meaning, purpose or social contribution to our participants' lives, such as art, crafts, gardening, community action or formal volunteering. Finding enough energy to allocate to these activities that are so necessary to wellbeing was often the biggest challenge shared by participants:

> *Socialising isn't as important as personal care, but I know that if I try and ignore my need for socialisation for too long, the need overwhelms everything else, depression kicks in and personal care becomes impossible.*
>
> Charlotte

> *I need to do hobbies, experience enjoyment, or contribute to the world in a meaningful way… I guess it isn't up there [in importance] with personal care, but I wouldn't have mentioned it if it wasn't something I struggle with personally.*
>
> Olivia

For people with ELCI, careful choice is needed each day over which activities to perform. For example, many participants said they could rarely or never manage household tasks. Others could only manage some paid work because other people did the household tasks for them. Sometimes people would have to let self-care slip, not washing for several days or weeks at a time, or not getting dressed into day clothes, in order to be able to manage other tasks, including the need for social connection. People with ELCI have to become experts in the management of their limited energy on a daily, even hourly basis, in order to maximise their goals. As Betty said, she has to have a cleaner and her partner does the cooking, as 'after work I have nothing left…no spoons'.

Health management

> *People with chronic illnesses need to walk a tightrope everyday just to keep themselves as healthy as possible.*
> Samantha

It is essential for people with ELCI that they have the space to manage their health. For participants with severe ELCI, basic personal care and health management could absorb all of their capacity for activity. Neglect of treatment regimes can lead to long-term deterioration in health and greater difficulty with self-care as well as all other activities, including work.

Health management tasks include taking medication; treatment regimes, such as physiotherapy exercises; attending healthcare appointments; and managing healthcare bureaucracy. These tasks occur on top of the normal personal, household, familial, social and work-related tasks that everyone participates in. They are therefore an additional drain on energy and capacity for activity, even though they are essential for the maintenance of future capacity. A further time constraint is created by the need for additional rest and even sleep on top of normal levels.

Participants felt that there was little understanding by non-disabled people of the energy costs involved in health management:

> *There's just no flicker of understanding of how much work, for many of us, goes into maintaining the health we have and that this work needs to be done before anything else is asked of us.*
> Charlotte

> *It's been a long, hard road to me accepting that my healthcare is my 'work'. The extensive treatment regime I have takes hours a day and if I didn't do it, I'd be sicker and die sooner.*
> Olivia

> *I have to do physio daily, aqua strength 3 times a week, and osteopath fortnightly to help manage pain, mobility and fatigue in order to keep working. I'm knackered.*
> Betty

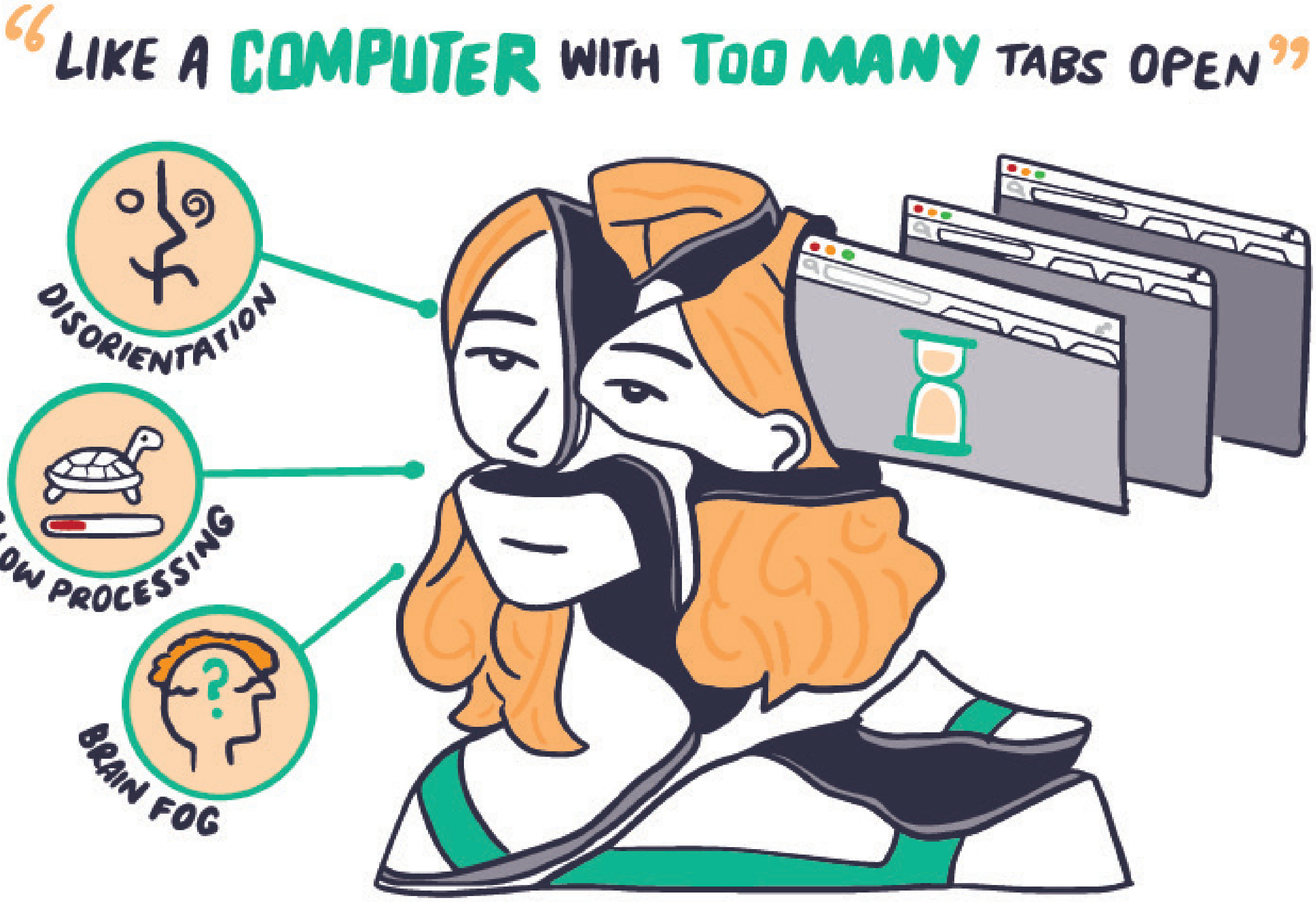
A spectrum of energy impairment

The impact of ELCI and energy impairment on daily living and work has a wide range according to the severity of disease. At the most severe end of the scale, people with ELCI are confined to their bed, often unable to tolerate light, noise or social contact, and needing help with personal hygiene and care. At the other end, a person with mild ELCI may be able to hold down a full-time job if they have adequate autonomy and control, albeit at the expense of social or leisure activities outside of work.

Most of our participants positioned themselves somewhere in-between these poles. Most were able to leave their home and take part in activities on occasion, but unreliably, only for short periods and only by incurring payback after any activity.

More research is needed with the chronic illness community to develop indicators that can convey the spectrum of ELCI and its impact on individuals. Based on our participants, even ‘mild’ ELCI rates as only 50 or 60 on the Bell Fatigue Scale, where 100 is no fatigue, placing them more in the middle than at the mild end of ‘fatigue’. There is therefore a need for fuller understanding of ELCI and its impacts to ensure that any terminology accurately reflects the lived reality.

Cognitive Fatigue



2. Employment and Social Inclusion with ELCI

The inclusion and participation of disabled people in society as a goal of government policy has largely been framed through their position in the labour market. This trend increased from 2008 with the 'labour market activation' of disabled people through welfare reforms.[16] From this perspective, paid work is seen as the key to citizenship; an individual's main contribution to society; and the way in which people gain personal fulfilment and social integration.[17] However, the relationship between paid work, social inclusion and social citizenship for disabled people has long been called into question by disabled researchers and activists.[18]

Consistent with the ethos of emancipatory disability research, our study focused on the experiences, aspirations and goals of disabled people with ELCI, rather than on an existing policy agenda. This meant exploring what it meant for our participants to be included and participate in society, as well as considering how paid work may contribute to social inclusion.

When asked about social inclusion, our participants reported that having a sense of meaning or purpose in life was very important to them, as was social connectedness. This included achievements; the ability to express themselves and connect with others; learning new skills; earning an income; and contributing to society. As previous studies have noted, this belies the stereotype of passive dependency associated with sickness benefit recipients.[19]

Routes to meaning and connectedness include family relationships; peer support; community work; religious participation; and hobbies. In contrast to paid work, these activities do not include pressure to perform at certain times to certain standards, and the absence of these pressures means that activity can be tailored to capacity on a moment-to-moment basis. This removes the harm that paid work often brings. Consequently, people with ELCI may achieve social inclusion better through unpaid, informal activities than through formal paid employment.

> *Some people need a place to fit into and get that feeling of completeness through having a job, a place to be and some people need to feel that their skills are being used in a positive way, that they are providing something good or beneficial for others. Also, the drive of work and reaching targets, fulfilling tasks, can keep up a level of exercise and fitness that is needed to maintain health. But this shouldn't be confused with paid, contracted work where the person is tied into something that is detrimental to their health.*
> Amanda

The challenges of work with ELCI as reported by participants are a complex interaction of impairment factors with social, structural and environmental factors. While it is not always possible or accurate to separate the two, we explore impairment factors of work and health first, and systemic barriers second.

Health-related barriers to work

Energy impairment

With energy impairment, capacity for work is limited by the amount of capacity for activity in total. People with ELCI often have very low capacity for overall activity, and this capacity must first be devoted to essential tasks including personal care, domestic management, health care and the human right to, and need for, rest and leisure. Many of these daily living activities cannot be traded for work but are instead essential activities that make work possible.

> *I would only be able to work short hours, maybe a maximum of 3 hours every other week (and that's if I'm 'well')…*
>
> *The 3 main ways [my health condition] is a barrier to work for me are: fatigue/low energy, breathlessness, and an extensive daily treatment regime that makes fitting work in around it extremely difficult.*
> Olivia

For many people with ELCI there is no energy left for work after the essentials of daily living. Those participants who were in work were all dependent on either a partner or a social care package for cooking and household management activities, and in some cases also needed help for elements of personal care, in order to free up energy for work. Such people could not reasonably be assessed or treated as fit for work, yet should also be given the support they need to work if they want to work. Another major energy cost that had to be considered was commuting:

> *Travelling: it sucks the life out of me! The car isn't too bad but public transport is an exhausting nightmare and no-one can tell you're suffering.*
> Olivia

Energy impairment is fundamentally incapacitating. It differs from the lay understanding of fatigue as an unpleasant sensation which can be overcome with determination.

The main way of adjusting to energy impairment is through reducing hours of work, including to zero. Providing support in other areas of daily living can help to create more hours for work, if the individual's preference is to put health and energy into work over other essential tasks. The importance of social care provision for support with activities such as preparing food, keeping a home clean and managing money must be included in discussions around work capability.

Payback and fluctuation

Crucial to the understanding of energy impairment is the concept of payback. Exceeding one's available energy budget results in increased symptoms and greater incapacity following any mental or physical exertion. This explains why work may be possible for one hour per day but not four hours per day; or one day per week but not three days per week:

> *Every task from "basic" personal care to filling in forms/dealing with people/ housework etc takes energy and for each event there are days worth of payback where I'm not able to do very much at all.*
>
> Rebecca

> *When I have a social worker assessment I have to take a day's annual leave and then do nothing but lie down in the dark and meet my bodies physical needs (food, drink, loo) for the rest of the day to have a chance of avoiding a crash (loss of meaningful functioning for several days). I don't think that's a 'trade-off' in the way healthy people would understand (e.g. 'if I eat this cake, I'll need to go to the gym')*
>
> Samantha

> *Pushing myself just makes me feel totally spaced out and then I am not safe to myself or other people*
>
> Tricia

In addition to greatly reduced overall capacity for work is the unpredictable fluctuation that comes with many forms of ELCI. Participants stressed that having a fluctuating condition renders social commitments or obligations fraught with the possibility of having to renege on commitments. Within work situations this is especially heightened. Some participants had experienced stress and anxiety at their inability to meet contractual requirements of work, due to factors such as conflict with managers and colleagues, and personal disappointment with one's self:

> *Not being physically reliable to even turn up for work can add psychological stress. I never know if I'll be able to arrive on time.*
>
> Hugh

> *My symptoms are highly erratic, and they make it impossible for me to work anymore as, even on a very good day, I can never be sure if I will last a day.*
>
> Phil

Cognitive dysfunction

Cognitive dysfunction has a severe impact on capacity to work as it reduces the clarity, accuracy and speed of thought and therefore reduces the quality and quantity of work. 'Brainfog' makes it difficult to follow speech and instructions; engage in conversation; carry out basic arithmetic; and make good decisions. All of these issues negatively impact a person's work and, depending on the sector, could result in danger or harm to the person and others.

Unlike physical fatigue, which can be managed by using mobility aids such as a wheelchair, there are no available aids for reducing cognitive fatigue and thus very little scope for alleviation or amelioration of cognitive fatigue in order to increase capacity for work.

> *I can't find words, particularly nouns and can't string a complete sentence together. I was taking a [course] but the tutor noticed that my work started well but then trailed off. I realised it was the length of time I spent on it - if I went into the 'tired zone'*
>
> Amanda

> *Fatigue and brain fog make mental functioning difficult and limit the amount I can do in a day. I have nothing spare for work after doing what I need to do to take care of myself and my family.*
>
> Faye

Sensory sensitivity

People with ELCI experience a diverse range of illness symptoms on top of the core elements of physical fatigue, cognitive fatigue and pain. The most notable additional issue raised by our participants in relation to the workplace was sensory sensitivity. Participants reported that levels of noise, light, temperature and sometimes environmental chemicals and perfumes can exacerbate energy impairment and reduce physical and cognitive function. These features of workplace environments are especially difficult to adjust. They are also common issues during commuting.

Participants suggested that working from home was often the only way to manage noise, lighting, temperature, and air purity levels. Some participants also struggled with the common fabrics and styles of work clothing, and home working could again be a useful adaptation where it allowed people to work in comfortable clothing, including pyjamas. Home working is an important and potentially effective adjustment for ELCI both in terms of avoiding the energy drain of commuting and also for managing sensory sensitivity.

> *I know this is kind of trivial but I've noticed recently that my clothing can make quite a big different to my pain level. Almost everything I wear is cotton now which has really reduced my issues with skin hypersensitivity. I think I'd really struggle to find formal office appropriate clothing that didn't hurt (within a reasonable price range).*
>
> *Also because of the m.e. and my general struggles with temperature control, I'm often either inappropriately boiling or I need several layers and a blanket and possibly a heat pad to warm up enough to stop shaking. Can you get away with being a sentient pile of blankets in most work spaces?*
>
> Charlotte

Structural barriers to work

Whilst energy impairment and ELCI restrict capacity for work in and of themselves, they also interact with cultural, structural and systemic barriers. These barriers could and should be addressed to enable people with ELCI who have some capacity for work to fulfil their right to decent paid employment. The socially constructed barriers to work include the organisational patterns of work, cultures of management, poor attitudes towards ELCI, and a lack of targeted employment support policy and provision for disabled people with ELCI.

> *The more I've recovered and tried to interact with society, the more walls I run into that are there because government and society don't understand chronic illness. So many of those walls seem to be there just because no one ever thought about us. They're a thoughtless default, not an active choice and at least some of those defaults seem like they would be easy to change.*
>
> Charlotte

Pace and times of contractual work

Paid employment is unlike other activities of daily living because it allows for far less autonomy in pacing and prioritising tasks. Work generally cannot be managed with the same strategies that are used to ration limited energy and respond to variability in other areas of life: other activities can be traded off against each other in ways that are not possible within contractual employment. For example, sometimes participants chose to forgo personal hygiene in order to maintain online social contacts when they could not manage both in one day. Other times they chose to over-exert themselves in an activity that brought particular meaning or social connection, knowing they could recuperate from payback on following days. Sometimes they deferred tasks for a 'better day':

> *Some days I can't look after myself, i.e. cook and clean… I manage because I keep enough in the larder to get through a few days if I'm mostly in bed, and for the rest there isn't much that won't wait a day or two. This isn't the case with paid work.*
>
> George

> *I never know how I am going to be or what level of cognitive issues I'm going to be dealing with.*
>
> Tricia

The contractual nature of paid work typically determines set hours and times for work and imposes deadlines according to organisational demands. This goes against the strategies for energy management deployed by participants. Unfortunately, currently most paid work does not support the level of autonomy required to manage ELCI, which involves highly-honed strategies of pacing, rationing and 'budgeting' energy on a daily or hourly basis.

> *Fixed times and fixed hours are just impossible and that has to be accepted as another starting point.*
>
> Phil

The requirement to meet scheduled times and deadlines not only disables health management strategies, but also creates "extra pressure" which in itself is an emotional stressor that can cause deterioration in health:

> *The stress of having to be monitored at work to make sure you 'perform' to a satisfactory level is pretty much cruelty to people like us, isn't it? the extra pressure, the worry?*
>
> Phil

Management culture

Several participants mentioned 'micro-management' in the workplace as a significant barrier to remaining in work. A culture of management that measures time and attendance rather than results and performance is especially disabling to people with ELCI because it directly interferes with health management strategies that require flexibility.

> *A lot of the time, it's not that I can't do the job... I can achieve the outcomes but not by the method which, for a lazy manager, is the easiest way to supervise...*
>
> *I can write a document at my home to a high standard as I'm less exhausted because I can lie down while doing it and there are no interruptions from others. A good manager doesn't need to see me in person to know I'm doing my work - they manage by results. But a lazy manager would require staff to be in the office because they can SEE them working.*
>
> Samantha

Lack of suitable job opportunities and specialist job brokers

The nature of jobs excluded many of the participants from engaging in paid employment. Some participants who were not in employment said that they might manage a role if it were for fewer than 16 hours per week, but roles of this nature were very hard to find within mainstream labour market:

> *How can I find a job that only needs an hour a day - and not every day?*
>
> Tricia
>
> *To sum it up I'd need the following: Flexible working hours, a flexible workload, telecommuting facilities and most crucially, an understanding and sympathetic employer.*
>
> George

Participants strongly felt that their skills could be usefully deployed by employers prepared to tailor roles to their capacities rather than forcing them to fit into existing structures:

> *I think a lot of companies could offer something to people who struggle for whatever reason with the normal 9-5 routine.*
>
> Eleanor

Conditions for the employment of people with ELCI would include, alongside very reduced hours, autonomy of working hours, the provision of remote working, and a trusting relationship with a line manager:

> *It would need to be on a project basis i.e. paid for each piece of work rather than a set number of hours a week. So it would have to be very flexible with me only 'on site' when face to face contact i.e. teaching delivery was needed; the rest of work would have to be from home. Conditions would have to be as such that complete trust would be needed to allow me to work from home as and when I can.*
>
> Denise

One participant had such a 'niche job' specially created for her by Astriid, a specialist job-brokering agency for people with long-term health conditions.[20] Apart from this provider, there appear to be no other agencies in the employment support provider ecosystem that specialise in supporting disabled people with ELCI.

Issues with disability disclosure and reasonable adjustments

Participants reported that the most challenging aspect of work – apart from ELCI itself – was the attitude of managers and colleagues, which impacted not just the reasonable adjustments that were made available but the environment in which these were sought and negotiated. All participants who had left employment due to ELCI reported hostile relationships with managers, and sometimes colleagues, surrounding their requests for adjustments, the denial of these requests, and their eventual departure from work. One of the participants who was in work reported that the lack of understanding displayed by her line manager was so bad that it out-weighed all the reasonable adjustments that had been made, and could force her to leave her job.

> *I did ask for reduced hours and was told "no." It all got worse from there and I had a truly hideous time.. So I left after realising it was only getting worse from my [employer] and my health conditions. I should have gone for "constructive dismissal" but I was so emotionally and physically exhausted and just couldn't face anything else so didn't.*
>
> Rebecca

Some reported that these circumstances of conflict and strain had led to mental health difficulties compounding their physical health difficulties.

> *I experienced such a level of stress at work that, looking back, I think it gave me a touch of PTSD, and bent my personality out of shape.*
>
> George

Our first phase of research found a social perception of 'fatigue' as a universal or 'normal' condition that is distinct from stereotypes of 'disability' as pathological difference.[21] Participants reported that, especially in the early or pre-diagnostic stages of chronic illness, fatigue and other chronic illness symptoms were routinely interpreted as laziness, lack of commitment and unreliability by others, including employers, and sometimes by themselves. The dismissal of fatigue as a form of impairment, and the internalisation of disability denial, pose enormous barriers to disability disclosure within work. It prevents employers from understanding energy impairment in the context of their legal duties to make reasonable adjustments under the Equality Act. Reasonable adjustments that could help with job retention are missed. Even where reasonable adjustments were granted, negative attitudes about fatigue on the part of line managers and co-workers could outweigh their benefits, according to participants:

> *Attitudes of colleagues is crucial to the wellbeing of a chronically ill employee in my experience; unless they 'get' why the person is seen to have extra support this can lead to serious isolation and bullying.*
> Denise

The terms energy impairment and ELCI were developed in order to differentiate the lived experience of chronic illness from the universal experience of 'fatigue'.

Issues with self-employment

Despite self-employment offering potential opportunities for flexible working, it was not viewed as a solution. Instead, it had its own problems, in particular around the lack of co-workers to take on difficult tasks or to take over during sickness absence. Self-employment, like paid employment, was engaged in as much from financial necessity as from desire to work, and was engaged in at levels that were harmful to health due to the lack of financial and business support for periods of sick leave.

> *I'm self-employed. Some say that this is the ideal situation for the disabled, that we can pick and choose our hours to suit our health. What nonsense…I have no one to cover my work when I'm sick and no one to share parts of my job that I find hard due to my health.*
>
> *I feel isolated and alone, with no support.*
> Betty

Workplace adjustments and their limitations

Participants suggested some workplace adjustments and adaptations that could save energy, accommodate pain, or reduce the impact of symptoms such as sensory intolerance. These included: ergonomic seating to reduce pain; the facility to rest within the workplace (e.g. in a quiet room for lying down); the avoidance of open plan office spaces, in particular to allow control over lighting, noise and temperature; a relaxed dress code to allow comfortable clothing; and the provision of a parking space close to the workplace. However, they stressed that, given their level of energy impairment, none of these adjustments on their own would necessarily increase their hours of productivity enough to enable them to sustain work.

> *I want disabled and ill people to be accommodated in the workplace as much as possible, but I also personally need to accept my limitations. I don't think there is an adaptation that could be made that would make a real difference to me.*
> Olivia

Aids and adaptations can be important as workplace adjustments for people with milder forms of ELCI but they are less enabling of work than for other forms of impairment, e.g. mobility impairment and sensory impairment.[22] They are less likely to make a material difference to people with severe ELCI in terms of managing a workplace environment. This is why recognition of ELCI as a distinct impairment type is so important.[23] People with ELCI need adaptations if they are to be able to do some work, but will also continue to need social security as their main and secure income stream.

‘Work is not good for me’

Participants universally reported that pushing through symptoms and exceeding available energy in order to meet the demands of work (or other activity) resulted in severe symptoms and reduced capability. The stresses of work, including the demands to meet quality and performance standards, created additional mental strain and typically resulted in participants working when they needed to be resting, and thus harming their health.

Understanding the lived experience of energy impairment and payback is crucial to explaining why work can cause health to deteriorate over the medium to long term. This is at odds with one of the founding principles of social security and employment policy, which is that work is good for health. We asked our participants what they thought about the government’s conviction that work is fundamentally good for health and promotes recovery.[24] They said this narrative shows how little policy makers understand of the reality of ELCI:

> *The idea that work can help heal a chronic, incurable medical condition is absurd.*
> Faye

> *To work would mean that I could not physically care for myself, feeding etc, so I would live on junk food, live in a filthy house and never have chance to chase all those medical things that seem never ending. Work would not 'enable my recovery', but my decline.*
> Tricia

> *Work can catastrophically damage health and worsen quality of life which is not helpful and branding all work as "good for health" is a reducing the issue to absurdity.*
> Charlotte

Desire to work

Despite recognising the harm of paid work, the desire to engage in paid work was common amongst our participants. Their work ethic was strong.

Some wanted to work and were prepared to sacrifice their health or forgo social or leisure activities in order to do so. This was particularly the case for younger participants who had become ill before having much opportunity to participate in paid work. In these cases identity was strongly tied to professional occupation, or work provided personal and social development.

> *We don't have kids and are both pretty career-focussed, so giving up social life for work is something I did before I got sick, and so doesn't feel a burden now.*
> Samantha

> *I cannot see myself never working again. I have come close and have been advised in the past to change professions but I really enjoy my job and I'm bloody good at it. It would break my heart to walk away from it.*
> Betty

In contrast, older participants were more likely to stress the importance of health management as a priority; and the recognition that self-worth is inherent and not dependent upon activity or earnings. These participants typically had a long career behind them and had experienced deteriorating health in work. They were also more likely to assert the right not to work, which could include recognition that they had previously worked.

> *I refuse to feel guilty for my lack of work. I started work at fifteen years of age. I brought my kids up alone - and worked - and put myself through night classes, university, became a teacher. I've done more work than most in my lifetime and it's that work that has put me in the situation I'm now in.*
> Amanda

> *A lot of the time it takes all my energy to shower and dress. Some days I can do a little housework and cooking. If I'm completely honest after working for nearly 40 years before becoming sick I would rather use my limited energy to do something nice for myself.*
> Eleanor

The current social security and active labour market systems take a binary approach to work and worklessness, which assumes that those not in paid work do nothing and are 'languishing', directionless and even worthless. In reality, our participants worked hard to reconstruct lives of meaning and purpose and contribution after developing chronic illness, and were neither languishing nor directionless. However, the benefits system undermined and hampered efforts to engage, by viewing activity with suspicion (as indicators of fraudulent benefit claims) or using activity as 'evidence' that a person could work and so reducing or removing their benefits. Refraining from activity because of fears of how it would be interpreted caused conflict for our participants, who wanted to use their abilities as best they could within their limitations, yet also needed financial security and an income on which to survive.

The majority of our participants felt that the features of paid work that were good for mental health could be better found through volunteering, community involvement or family commitments.

> *Work is helping me, a great deal. I'm learning a lot about myself, my capabilities, how to deal with people, gaining skills and confidence. It's helping my mental health certainly and it might be helping me improve some of my coping mechanisms a bit. It's not making my m.e. less severe and the improvement in coping/ management skills isn't enough to catapult me into a huge recovery.*
> Charlotte

> *The trouble is that starting with a 'work is good for you' ethic with chronic illness is just wrong. Being a useful part of society' is very right in many ways. it may lead some to actual work, some to helping with care of others, membership of clubs/groups, access to good therapy and sports facilities, being 'paired' with someone with similar problems to learn how others cope and teach others how you cope.*
> Phil

Conclusions on work

People with ELCI are limited in the amount, rather than necessarily the type, of work they can do. Managing limited and fluctuating energy in day-to-day living requires extreme flexibility and the contractual pace and timing of most forms of paid work are typically antithetical to this. Cognitive fatigue and its associated dysfunction pose major challenges to employment. The sensory sensitivities associated with many ELCIs create additional challenges within workplace environments.

We can broadly consider three categories of work capability with ELCI:

1. those who have no productive hours of energy for work of any kind because their available energy is used up on the essentials of daily living;
2. those who have capacity for a few hours per week (fewer than 16), usually with no predictability; and
3. those who can hold down regular part-time or full-time work but only at the expense of other areas of daily living, and with reasonable adjustments. Policy solutions are needed to address each of these groups.

The principle forms of adjustment for disabled people with ELCI within employment are:

1. reduced hours of work;
2. working from home in order to eliminate the energy demands of commuting, manage sensory sensitivity, and promote rest breaks;
3. flexibility over working times; and
4. autonomy over pacing of work activity and rest.

Aids and adaptations can be important as reasonable adjustments, whether in the workplace or at home, but these are less enabling for ELCI than with other impairment groups. Flexible working policies are key but are not often addressed to ELCI, resulting in missed opportunities and wasted talent. Covid-19 has demonstrated the feasibility and value of remote working and this learning should inform flexible working policies for ELCI in future.

The provision of social care support, especially for domestic tasks, is another important lever for enabling participation in paid work for this group.

Negative perceptions and misunderstandings around 'fatigue' and chronic illness create formidable yet unnecessary barriers to work. The widespread notion that fatigue is not a real disability stands firmly in the way of disability equality in work. Systemic disbelief of energy impairment affects disability disclosure and access to reasonable adjustments, and contributes to strained employment relations, sometimes causing unnecessary departure from the labour market.

Specialist employment support for disabled people with ELCI is almost non-existent, in contrast to other impairment groups such as learning difficulties or mental health conditions. As a result, generalised employment support schemes such as the Work and Health Programme are likely to fail and employers are not informed or incentivised to create job opportunities for people with ELCI.[25]

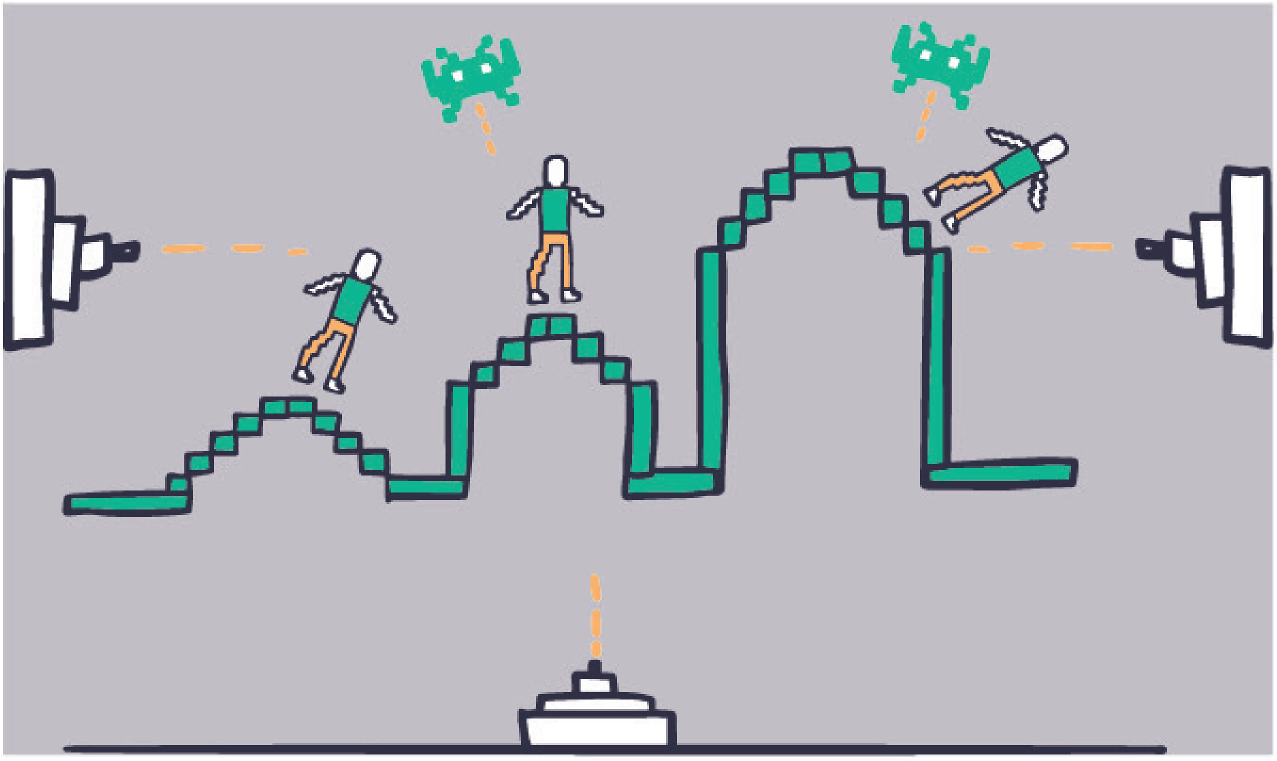
Paid work is not the straightforward route to social inclusion that policy makers imagine for disabled people with ELCI. Nor is the simplistic government mantra that 'work is good for you' appropriate for this group.[26] As previous commentators have noted, social value should not be defined solely as productive value. Indeed, work in itself can be disabling.[27]

It is crucial that the experience of people with ELCI is heard, not only to explain why some disabled people cannot work, but to promote the tools, practices and systems change needed to increase job opportunities for those who can.

The social inclusion of disabled people with ELCI requires support for meaningful activity and social connection outside of paid work, as well as promoting employment opportunities for those with enough productive hours to engage with work. It also crucially depends on having a foundation of income security from which to engage with the world of work. This is the subject of the next chapter.

Fluctuation

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



3. ELCI and Social Security

Many disabled people with ELCI have little or no capacity for paid work, and many others can only bring in earnings from part-time work. A robust social security system is, therefore, crucial to compensate for long-term unemployment, or to supplement low earnings. It must be adequate for supporting the right to social participation not just basic subsistence living, and it should address the additional costs of living faced by disabled people.

Following years of reforms to the welfare system, many of which reduced rates and eligibility for disability benefits, a UN Committee found the UK government guilty of grave and systematic violations to the rights of disabled people.[28] Personal Independence Payment (PIP) aimed to reduce spending on extra costs of disability by 20% by narrowing the definition of disability; Employment and Support Allowance (ESA) was designed to create a new class of disabled people who were unfit for work yet subject to reduced – even destitution-level – incomes and to prescribed 'work-related activity' under the threat of sanctions; the Work Capability Assessment (WCA) for ESA is linked with harms to mental health and increased suicide; the social security system as a whole leaves people insecure and destitute; and there is a climate of stigma, shame, hostility and distrust towards disabled people.[29, 30, 31, 32, 33]

This is the first study into the impact of the UK social security system on people with ELCI. Rather than attempting to address all the areas of concern raised by the UN as well as disability charities, we focus on the mechanism for qualifying for social security benefits, in particular the Work Capability Assessment (WCA), as well as some wider elements of the benefits and employment system.[34] This reflects the priorities of our participants. At the time of the research in 2018 none of our participants had been 'migrated' onto Universal Credit (UC) so this report does not address problems associated with the Universal Credit system.

Disability assessment and ELCI

The WCA for individuals applying for ESA (and now its equivalent under UC) is based on the model of health, disability and chronic illness known as disability assessment medicine (DAM).[35] Chronic illnesses causing fatigue and pain are characterised within the DAM literature as 'common health problems' that do not, in themselves, prevent work.[36] Its chief proponents, Waddell and Aylward, argue that people with so-called 'common health problems' bear personal responsibility for being out of work through their own 'attitudes' and 'motivation'. [37] 'Psycho-social factors' including psychopathology, illness deception, and the 'secondary gain' of financial support are suggested to be the cause of incapacity in claimants with chronic illness, despite a lack of evidence for these claims.[38] As a result, a key principle underpinning the WCA is that the experiences of impairment and disability reported by people with chronic illness are contentious, and not to be taken at face value.[39]

This research revealed a lived experience of ELCI that is starkly at odds with the narrative around 'common health problems' contained within DAM. ELCI and energy impairment - as opposed to common aches and tiredness – are highly debilitating conditions, restricting nearly all areas of daily living for our participants. It was ELCI itself, not lack of commitment to work, that prevented them from working, or from working full-time.

Our focus group participants were unanimous in their views of the WCA. They felt that the WCA was created to deny, rather than capture, their impairment and that consequently there was no interest within the ESA system or the DWP in their actual capacity for work.

> *The current DWP/government attitude to disability and chronic illness is largely to disregard the fact that for some people work is genuinely impossible. This enables them to construct the benefits system to literally design us out if it. Our lives don't fit their questions, and the system is deliberately constructed that way.*
>
> George

> *The government we currently have does not have our best interests at heart... I see no evidence that the current system has any intention of treating us with dignity and respect.*
>
> Olivia

Although the main focus of discussions was on the WCA and ESA, many participants mentioned similar problems with the assessment for Personal Independence Payment (PIP). This section therefore discusses problems with disability assessment systems generally.

Flawed assessment of ELCI

The WCA and PIP assessments ask people how they perform on certain activities in order to measure a range of cognitive and physical functions. They reduce 'evidence' of incapacity to observable, static forms of impairment and are designed to disregard impairment experiences that are not alway apparent upon observation within the assessment context, such as fatigue and pain.[40] The impact of energy impairment, however, can only be captured within the holistic context of daily living, and over a period of time.

Current assessment systems do not consider how performance on one activity can affect performance on another, and therefore implicitly assume and assess people as though there is no such effect. They set a threshold based on 50%, or the majority of days or majority of the time, for deciding whether a person can or cannot do a given activity.[41] This results in the over-assessment of the functional ability of people with ELCI. A person with ELCI may, for example, be able on any given day to do two out of a possible three assessed activities (e.g. cooking, washing and dressing). The assessment processes consider each activity separately, and assesses the person as able to do each activity on two out of three days (i.e., more than 50% of days or more than 50% of the time) and therefore not disabled on these activities. The person would be found fit for work or not to have substantial extra costs, when in reality they experience substantial limitation every day because every day they are unable to perform at least one of these activities. Additionally, they may experience significant, negative cumulative impacts from activities.

Participants perceived assessments as being decontextualised from daily living with no consideration of how limited energy has to be managed across the different foundational life tasks before any work is possible. There is no understanding that the energy required for work draws upon the same limited supply of energy that is often used up just to survive each day.

> *I have children at home and a disabled family member I care for several hours per week. Those responsibilities can't be dropped so instead I can do paid work. If I had no other responsibilities and lived alone in a small flat I could probably manage to work part time.*
>
> Faye

A key principle in disability assessments stipulates that any activity must be assessed against whether it can be performed 'repeatedly, reliably and safely'.[42] However, participants' experiences were that these criteria were not being properly applied to ELCI. There was a lack of consideration of the cumulative impact of activity; the suffering experienced during or for some time after activity ('payback'); the added time taken up by resting; and the unreliability of being able to perform an activity when required to. Thus, the WCA gives no indication of the crucial question of how many hours per week a claimant may, or may not, be able to work. Similarly, PIP does not consider how many activities a person can actually do each day or week, and therefore how much additional help they need.

> *I might be able to do something once or twice and be fine WHILE I'm doing it but I'll wake up the next day unable to move…*
>
> *Just because I could lift my handbag during the WCA doesn't mean that a) I'm not in pain and b) that pain and fatigue won't hit me really hard later on.*
>
> Kathy

One of the most intractable problems with ELCI for our participants was cognitive fatigue ('brainfog'). Several remarked that once their limited energy is depleted: "I lose words and can't follow conversations", or "I can't do basic tasks such as counting (money), making decisions, etc. I won't drive at all because my driving becomes erratic". This form of cognitive dysfunction with ELCI is usually directly related to overall stamina:

> *My work started well but then trailed off. I realised it was the length of time I spent on it - if I went into the 'tired zone'… I couldn't string a sentence together.*
>
> Amanda

'Brainfog', or fatigue-related cognitive dysfunction, is not assessed in ESA or PIP. This means that people with ELCI cannot have their capacity for cognitive activity assessed, and their overall capacity for work is therefore over-estimated.

Impact on health and social inclusion

> *When you feel well enough to do some charitable work, for nothing, to help those worse off than you, you feel as if you may be seen and thus lose benefits.*
> Phil

False inferences of the capacity for work of people with ELCI can come not just during benefit assessments, but also from members of the public reporting on individuals' activity to the DWP. This creates a fear of surveillance, described in previous research as a form of 'hidden conditionality', that holds people back from activity that could benefit their health and contribute to the community:[43]

> *Fear of being 'noticed' by the DWP has held me back from pursuing things for years. Physically I can't do much anyway, but when there is also a psychological barrier, it's almost impossible to find real meaning.*
> Olivia

Consequently, participants felt the contradiction of being required to appear at their worst at disability assessments in order to claim benefits but at the same time being afraid that if they were later seen performing at a higher level they could be reported to the DWP for fraud.

> *You have to describe things at their worst. This is fine except that it then leaves you open to accusations of lies and false claims if someone later sees you acting differently.*
> Amanda

A particular issue for people with ELCI was false inferences made on the basis of therapeutic exercise. Exercise is important for health management and maintenance, but it is not substitutable with paid work, nor is it evidence that paid work can be carried out on top of therapeutic exercise.

> *Doing 4 sessions of exercise a week [is taken as evidence that] I am more capable. In fact that exercise is essential so I can retain my mobility, and it drains me and greatly reduces what else I can manage each day. But without it I'd just go back to a lower capacity and greater levels of pain and physical disability.*
> Faye

Participants found the assessment processes for sickness and disability benefits to be depressing and degrading: depressing to have to set out in detail their illness and limitations, and reveal to themselves the extent of their illness; and degrading to report this to strangers who appear predisposed to judge their testimony as unreliable and even deceitful.

> *I found the process of answering the questions had a knock-on effect. I had obviously been 'kidding myself' about how bad things really were and, by answering their questions honestly, it was like a veil being pulled away and I was forced to see things as they are. In the days following I found myself increasingly depressed and unable to process what I had seen about myself and my life.*
> Amanda

Participants reported that reassessments occurred too often. Additionally, because assessment results were often inaccurate (even perceived as 'random'), reassessment meant that claimants lived with constant financial insecurity and fear. Coupling this with the inadequate incomes available on ESA, even when topped up with PIP, meant constant financial stress for those participants who needed ESA.

> *I think on reflection that most of my mental distress now comes from the uncertainty of the benefits system as I have no control over the outcome of any assessments.*
>
> Eleanor

> *My experience of the ESA and PIP assessment processes are that they're luck based… So much seems to be based on what assessor you get and whether they're competent or honest or know anything about your condition. That makes reassessment terrifying. I'm going through PIP assessment now and looking back, I think just getting the form caused a medium sized relapse that's lasted a couple of months so far.*
>
> Charlotte

Conclusions about social security

The Work Capability Assessment was intended to provide an objective, replicable assessment of a person's capabilities not dependent on diagnosis but valid for all impairment types. The WCA, however, remains completely unfit for the assessment of ELCI. Given that one third of disabled people of working age experiences impairment of stamina, breathing or fatigue, this is a serious failing.

People with ELCI are limited more by the amount, rather than the type of work they can do. But the WCA fails to account for energy impairment, payback, cognitive dysfunction, fluctuation, and the cumulative impact of activity. This results in misleading assessments that over-assess the work capability of people with ELCI. The WCA gives no indication of how many hours per week a person may be able, or unable, to work which is a key feature of employability.

Stigma and prejudice towards people with ELCI is rooted within the model of disability assessment, which systematically discounts and discredits the lived experience of chronic illness. Thus, stigma within the social security system as a whole cannot be fully addressed without a fundamental reform of disability assessments and the principles underpinning them. This research emphasises the importance of including accounts of impairment from the lived experience of people with ELCI when formulating systems and measures for disability assessment.

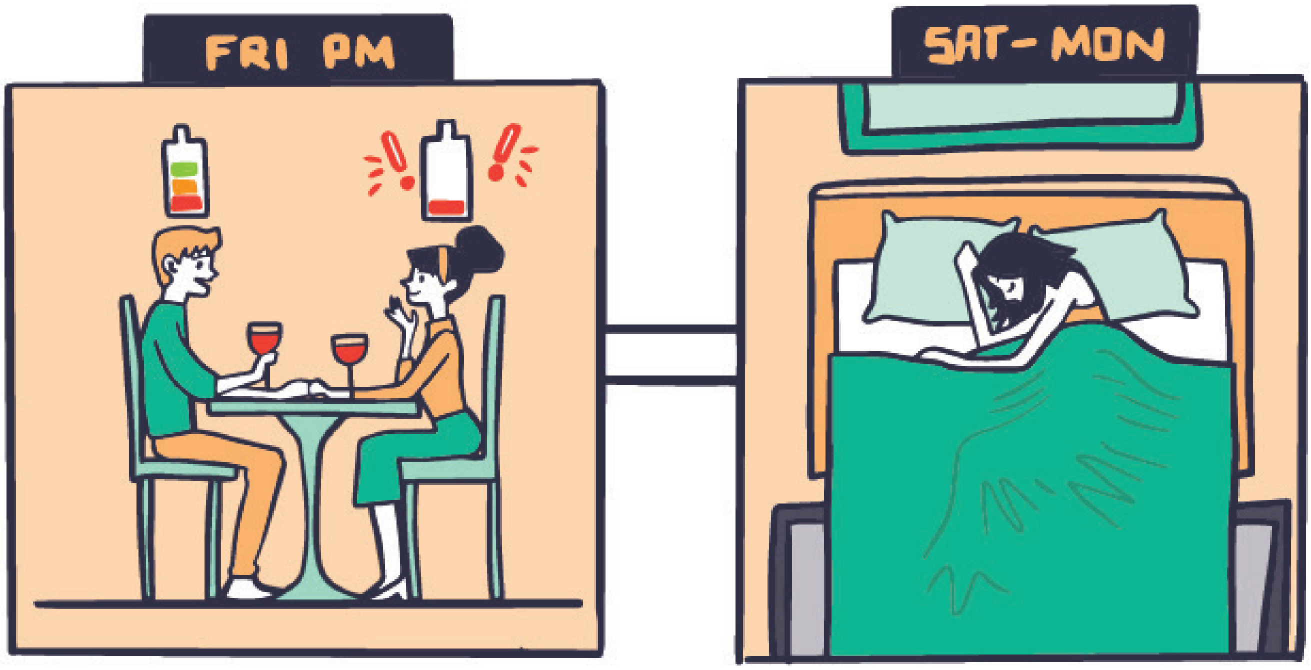
The WCA leads to insecurity of income because assessment outcomes are unfair, even random, and their frequency dominates people's lives. On top of financial strain, the disability benefit systems produces a deep-seated social insecurity due to the culture of distrust and surveillance that impacts on claimants, even outside of formal interactions with DWP and assessors. This aligns with the findings of numerous other studies into the social impact of welfare reforms.[44] This culture of surveillance and distrust inhibits people with ELCI from investing their limited energy on activities that promote health, wellbeing and social connection.

The WCA and wider benefits system undermines active health management strategies. For participants, the energy spent on fighting the system to obtain basic entitlements quite literally takes energy away from other essential life tasks. Self-care, health management, social connection and purposeful activity all suffer as a result, pulling participants further away from participation, inclusion and even work. In the language of the social model of disability, we conclude that the social security system constructs barriers to health and well-being, social inclusion and engagement with work, rather than dismantling them.

New systems and criteria for disability assessment are needed for both the extra-costs benefit (DLA/PIP) and the income-replacement benefit (ESA/UC). This need is urgent, not only because of the scale of failings in the current system, but in reflection of the prevalence of ELCI among disabled people.[45]

Payback

> “I SOMETIMES GO BEYOND MY ENERGY LIMITS, EVEN THOUGH I KNOW I'LL PAY FOR IT AFTERWARDS”



RECOMMENDATIONS

Promoting social inclusion for disabled people with ELCI requires a new approach that centres their particular experiences, needs and aspirations. Crucially, measures to improve employment prospects cannot succeed without a robust and enabling social security system. Although we list employment policy recommendations separately from those on social security, joined up policy making is key to improving lives. Employers, government and other stakeholders (including employment support organisations) all have a role to play.

1. Recognise ELCI as a type of disability

Cross-government departments and agencies should recognise people with ELCI as a discrete sub-group of disabled people, as part of the National Disability Strategy (Cabinet Office).

2. Promoting employment with ELCI

Employers should:

a. Understand ECLI and energy impairment as a form of disability for which employers have a legal duty to make reasonable adjustments. Key adjustments to enable people with ELCI to remain in, or take up, work include:

    - Adjustments to working patterns, especially reduced hours, flexible hours, (e.g. annualised hours), home working, remote access provision as we have seen through the lockdowns with Covid-19.
    - Workplace adjustments for those able and preferring to work within workplaces include (but are not limited to) parking spaces, resting spaces, ergonomic seating/reclining, the ability to control light, noise and chemicals (not open plan offices) and the capacity to take breaks during the working day.
    - Carving out niche roles tailored to people with ELCI such as by creating roles below 16 hours per week, reducing or removing travel requirements and redesigning job roles to increase employees' autonomy and flexibility.

b. Include ELCI within broader organisational Equality, Diversity and Inclusion initiatives including:

    - Disability awareness training produced and delivered by disabled people with lived experience of ELCI that challenges negative stereotypes about fatigue and chronic illness and outline key practical adjustments to support employees with ELCI.

- Fostering organisational cultures that support disability disclosure and reasonable adjustments for people with ELCI.
- Encouraging management practices to support worker-led flexibility.
- Job role re-design to maximise autonomy, trust and responsibility to empower employees with ELCI to manage their health condition and to work productively within safe energy limits.

Government should:

a. Adopt a targeted approach to employment policy and support provision for people with ELCI, not maintain the one-size-fits-all approach which has failed both individuals and employers.

b. Bolster rights to flexible working for disabled people as a reasonable adjustment, including reduced hours, flexible hours, home working and remote access technology.

c. Support the development of job carving agencies to connect employers with jobseekers with ELCI and work with employers to create tailored roles to maximise employee sustained productivity, while maintaining health and well-being.

d. Commission a diversity of intermediaries within the employability ecosystem, including specialist and disabled people's organisations to provide specific employment support for people with ELCI.

e. Provide programme participants with a choice of providers to allow them to access specialist support.

f. Improve the Access to Work scheme by:

- Increasing funding to cover a greater range of aids, adaptations and assistance
- Assessing applications and deliver support in a timely manner to facilitate work and avoiding lost employment opportunities
- Simplifying the application process for both employees and employers
- Promoting knowledge and understanding of the scheme amongst employers
- Making the scheme more accessible to self-employed workers
- Expanding the scope of Access to Work to include funding for disability leave for temporary cover to support the employment of disabled people with fluctuating conditions such as ELCI

g. Increase funding to social care, with a particular focus on the provision of support for household tasks, to free up capacity for activity from those who want to work.

h. Support volunteering and informal work as routes to social inclusion and to improving well-being, as well as steps on a journey to employment.

3. Social Security Reform

We echo recent calls from a number of think tanks and user-led projects for a new, fairer, social security settlement in the wake of Covid-19 which is fit for purpose.[46] We endorse proposals for a guaranteed decent income, with greater security, removing conditionality and sanctions, and a basis in dignity and respect towards claimants.[47]

The damaging stigma and distrust within the current system cannot be redressed without fundamentally overhauling the Work Capability Assessment and the principles of Disability Assessment Medicine. As such, government should:

a. Redesign the Work Capability assessment in partnership with disabled people with ELCI, as well as other impairment groups. The principles of disability assessment should be rooted in lived experiences of impairment and work. This entails:

   - Rating the range of work capability according to the number of productive hours that can be repeatedly and reliably sustained in work, as part of a holistic assessment model
   - An understanding of when paid work is unsafe and causes deterioration due to payback and need for pacing and rest
   - A relational approach that explores how limited energy is allocated across all tasks of daily living, including self-care, health management and domestic and financial management, as well as in work
   - Taking particular account of the impact of cognitive fatigue ('brain fog') and related cognitive dysfunction on work capability
   - Training assessors with knowledge and understanding of the lived experience of ELCI, as well as more specialised medical knowledge of the conditions with which claimants present with
   - Restoring trust between assessors and claimants by allowing for a longitudinal and holistic assessment of work capability, rather than tick-box model of assessment

b. Redesign our social security system so it protects health and wellbeing and creates a foundation for social inclusion by:

   - Reducing the unnecessary frequency of reassessments that drain energy from health-promoting activity
   - Increasing funding for advice and advocacy services to provide support for the claims process, especially for people with cognitive dysfunction due to ELCI and enable correct decisions first time
   - Simplifying the appeals process, including ending the barrier to justice of Mandatory Reconsideration

c. Increase benefit levels to a decent income reflecting Minimum Income Standards that supports broader social participation.

d. Increase income security to enable safe experimentation with work and other forms of social contribution, especially for those in part-time or low hours of work and those who are self-employed through: a lower taper, more generous criteria and long run-on periods before a person who increases their activity level can be reassessed for fitness for work.

e. Compensate for reduced earnings from reduced hours of work, without pressure to increase hours of work, in order to qualify for payments.

f. Personal Independence Payment must be more reflective of the additional costs faced by people with ELCI for social participation.

4. Recommendations for further research

This research has provided a unique and unprecedented insight into ELCI by those who can best account for it: those who experience it every day and can articulate its impact on their everyday lives and work. There is an urgent need for more interdisciplinary research to:

- Develop indicators for a spectrum of energy impairment in partnership with disabled people, with a set of indicators of severity, to aid in the assessment of work capability and employment support and other policy areas
- Provide detailed briefings on reasonable adjustments in workplaces in partnership with external partners working with businesses of all sizes and sectors
- Further research with employees and their line managers, including from a broader range of occupations, to identify good practices in the management of ELCI in workplaces
- Examine how improved employment support can be provided to people with ELCI through both government-contracted programme providers and other organisations, including disabled people’s organisations
- Cross-national comparative research on social security and employment systems responsive to the particular requirements of ELCI
- Research into the impact of ‘Long Covid’, as an ELCI, on people’s engagement with work and employment and their needs for social security

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Chronic Illness Inclusion

Chronic Illness Inclusion (CII) is a voice for disabled people with energy limiting chronic illness, energy impairment and chronic pain, led by lived experience. CII grew out of the Chronic Illness Inclusion Project, an emancipatory research project under the DRILL programme of disabled-led research which began in 2017. In 2021 CII became a Disabled People's User-Led Organisation.

Read more about CII at: www.chronicillnessinclusion.org.uk

Email CII's Director, Catherine Hale at: catherinehale@cii.org.uk

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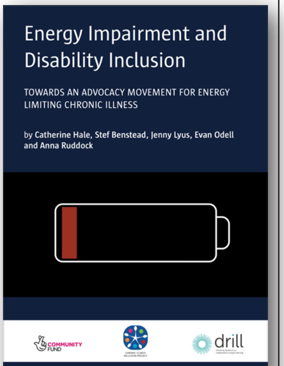

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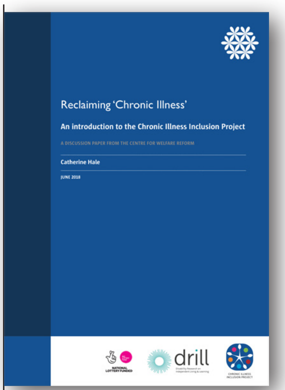

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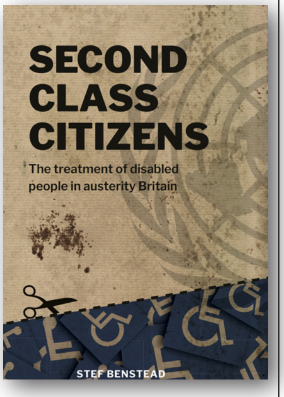

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