



astriid

What are Energy Limiting Conditions?

An introduction to including people with energy limiting conditions in the workforce, aimed at employees and their managers.

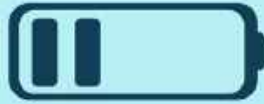
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Introduction

Our ‘invisible talent pool’ of candidates at Astriid say that the lack of understanding of energy limiting conditions (ELCs) is among the biggest barriers they face to getting in, and staying in, work.

This guide introduces a new way of thinking about the many long term health conditions that involve fatigue and pain. We hope it will spark open conversations between employees and managers and lead to effective support that enables people with ELCs to fulfil their potential at work. This guide may also be of interest to Human Resource practitioners, DEI leaders and employee resource groups for disabled staff.



“ I have lived with an energy limiting condition for decades, but for a long time, I didn’t have the language to adequately convey my needs. The concept of ‘energy limiting conditions’ grew out of my work with Chronic Illness Inclusion. Our research showed a gap in understanding of this form of disability among policy makers and in society. This meant that, too often, our needs remain invisible and unmet. Through working with Astriid, I discovered the pioneering movement for disability inclusion at work. I hope the knowledge about ELCs shared here can be a tool for change in this important work. ”

Catherine Hale

1. Key facts about energy limiting conditions

What is an ELC?

ELCs are a type of disability. They limit the overall amount and pace of activity an individual can do, rather than the type of activity. These conditions also tend to affect the reliability of activity.

ELCs typically affect many parts and functions in the body, rather than affecting a specific organ or limb. Therefore, they often span several categories of disability, such as mobility impairment, cognitive impairment and sensory sensitivity.



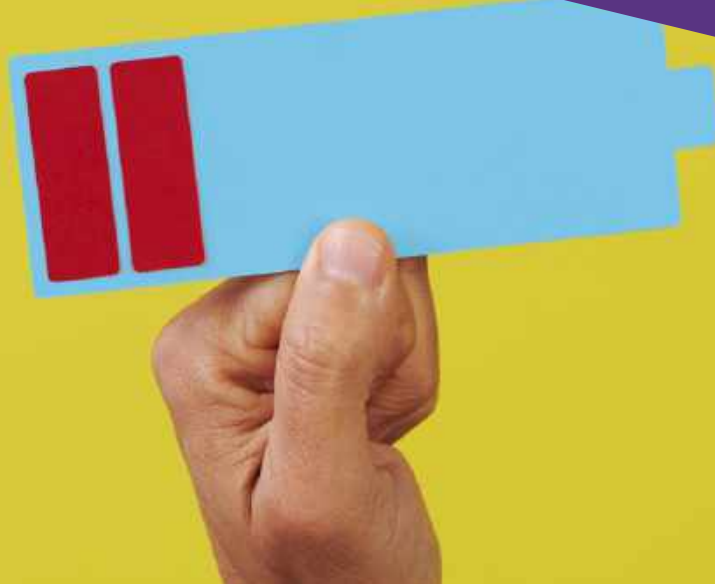
With an ELC, it is helpful to think about impairment or disability as occurring over a period of time, such as a day or week, rather than the snapshot of what an individual can perform in the moment.

Which health conditions are energy limiting conditions?

Around 4.7 million people in the UK have an energy limiting condition that significantly restricts their day-to-day life. 1 in 3 disabled people of working age has this form of impairment. UK disability statistics record this as 'impairment of stamina, breathing, fatigue'. Some people refer to this as 'energy impairment' in preference to 'fatigue'.



ELCs are a very common type of long-term health condition or disability. Despite this, there is very little training available to help employers and managers understand and support people with this type of disability at work.



Which health conditions are energy limiting conditions?

There is no definitive list of ELCs, however there are some common examples. The ELC umbrella covers conditions where fatigue and energy impairment are defining features, such as Long Covid, Myalgic Encephalomyelitis/chronic fatigue syndrome and chronic lyme disease. It also covers many more conditions where fatigue or energy impairment are often present. This includes:

- musculoskeletal conditions like fibromyalgia, Ehlers Danlos Syndrome and rheumatoid arthritis
- respiratory conditions like chronic obstructive pulmonary disease and cystic fibrosis
- cancer and the treatment effects of chemotherapy
- neurological conditions like multiple sclerosis
- gastrointestinal conditions like Crohn's Disease and irritable bowel syndrome
- heart and circulatory conditions
- auto-immune conditions like lupus and mast cell activation syndrome
- inherited metabolic disorders
- mental health conditions and being neuro divergent can also be associated with fatigue and limited energy.



Health conditions affect everyone differently and individuals often have more than one condition. When broaching the subject of health and disability at work, it helps to ask about the impact of a health condition or combination of conditions, and the measures that can mitigate this impact, rather than focusing on the diagnosis or cause.

ELC is not a medical term for categorising disease, but a label used by disabled people to describe their experience.

The term ELC doesn't describe the cause of a health condition, but its impact, in other words, how it affects day-to-day life and work. It is inspired by the metaphors that have spread through disability and chronic illness communities as people have sought creative ways of helping family and friends to better understand their experience.



It's important to learn about experience and identity from disabled people themselves, not just from medical guidance.

How do ELCs affect day to day life?

There is a wide range of impairment with ELCs, depending on how an individual is affected by their condition(s). Someone with mild energy impairment may manage to hold down a full-time or part-time job, but at the expense of any social or leisure activities, or quality of life, outside of work. Alternatively, someone with severe energy impairment is generally confined to their home or bed and has no capacity for activity other than the everyday management of their condition, which they may require help with.



If you know someone affected by an ELC, don't assume you know the impact it may have on another person. Not everyone with an ELC is able to hold down a job, but with effective support many can be valuable employees and colleagues.

2. What's it like to live with an energy limiting condition?

Research by Chronic Illness Inclusion and Astriid has identified the features of ELCs that are most commonly reported in relation to employment. These include energy impairment, cognitive fatigue, fluctuation and 'payback'.

Energy impairment

Having limited energy, or energy impairment, is different to feeling tired. It is often compared to feeling like a faulty battery that never fully charges, runs out of charge quickly and needs frequent periods of recharging. Small daily living and work tasks may completely deplete a person's available energy, requiring them to stop and 'recharge' frequently throughout the day. This can have an impact on the number of hours an individual can work, as well as the pace of work. However, once an individual has learned to manage their energy 'budget' effectively they can be just as productive within their limits, if not more so, because they have learned to prioritise tasks and eliminate distraction.

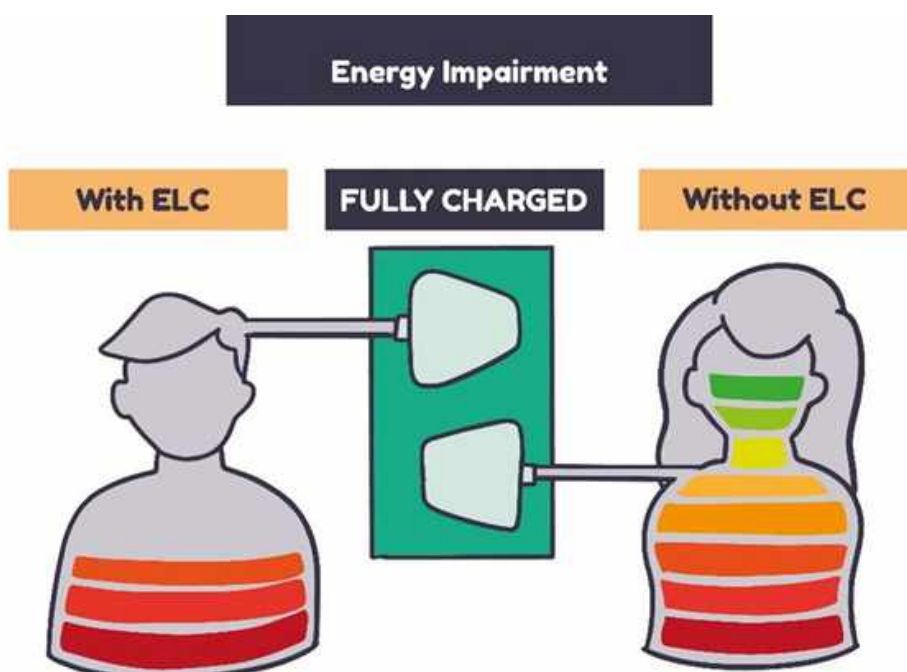


Illustration: Laura Evans @niftyfox

Cognitive Fatigue

“LIKE A COMPUTER WITH TOO MANY TABS OPEN”



Illustration: Laura Evans @niftyfox

Cognitive fatigue and dysfunction

87% of people with ELCs report that cognitive fatigue limits the amount, and sometimes the type of work they can carry out.

This is sometimes referred to as 'brain fog', although some people feel that this term minimises its effect. Cognitive fatigue causes real limitations and means that tasks requiring concentration will only be possible for shorter periods of time. In some conditions, such as Long Covid, fibromyalgia and ME/CFS, short-term memory, communication and executive function are impaired. This means that everyday tasks like reading, holding a conversation, driving, or typing can be more difficult or must be limited in duration.

Although cognitive fatigue is less easily accommodated, e.g. by mobility aids, than physical fatigue, making adjustments to how work is scheduled, such as allowing for rest and pacing, can be very effective.

Fluctuation

89% of people with ELCs report that fluctuating or episodic symptoms limit their employment opportunities.

Many energy-limiting conditions have a fluctuating pattern of symptoms. This means an individual's capacity for work may vary unpredictably, from week to week or day to day, or even within a day. There may be certain external triggers that lead to a 'flare up' (a recurrence or worsening) of symptoms, and individuals may learn to 'pace' themselves to avoid triggers. However, with many ELCs, fluctuation is part of the course of the condition itself and may be unavoidable.

Managers often worry that fluctuating conditions lead to unreliability in a job. However, with the right support and with worktime flexibility built into a role, employees with fluctuating conditions may have an advantage in terms of resilience and adaptability to change.

Fluctuation

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

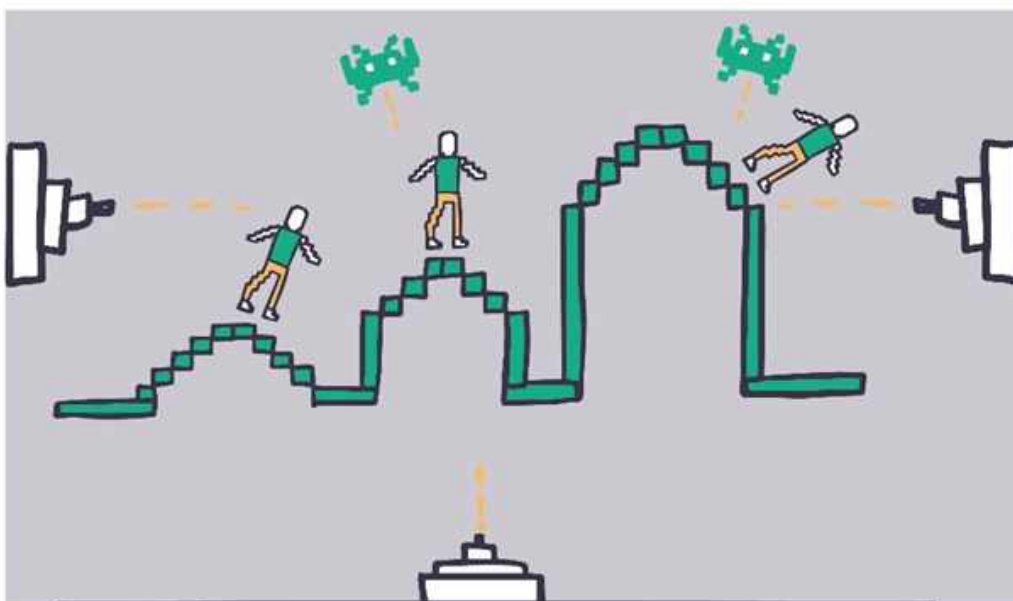


Illustration: Laura Evans @niftyfox

'Payback' for exertion

87% of people with ELCs report that 'payback' affects their ability to perform at work. Payback is a term sometimes used informally to describe the worsened symptoms and/or increased incapacity that somebody experiences as a consequence of over-exertion. Over-exertion happens when a person exceeds their available energy. In ME/CFS and Long Covid this is also called 'post exertional malaise' or 'post exertional symptom exacerbation'. Payback can mean longer periods of recharging and recovery times are required for a person to get back to their baseline.

Payback is one of the ways that ELCs are invisible to colleagues. An individual may appear to be able to perform a task well at work but the payback they experience afterwards, and their inability to repeat the task, is not seen or understood, leading to them masking their difficulties. However, flexibility in work time arrangements and scheduling can be very effective in accommodating payback.

Payback

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



Illustration: Laura Evans @niftyfox



Additional common symptoms

The following are also common symptoms of an ELC which may require workplace adjustments:

- Chronic pain – muscle and/or joint pain
- Gastrointestinal symptoms – affecting bladder or bowel continence
- Autonomic dysfunction – such as orthostatic intolerance, i.e. limited ability to stand or be upright.
- Sensory sensitivity
- Nausea, dizziness
- Breathing difficulties
- Migraine and flu-like symptoms
- Co-occurring depression and/or anxiety. This may be caused by the disease process itself or be a reaction to loss and isolation

In Section 4 we will further explore the adjustments and support measures that managers can implement in order to mitigate the effects of these feature, enabling individuals to perform at their best.

3. Energy limiting conditions and society

The disadvantage that people with ELCs experience at work can be the result of social attitudes and socially constructed barriers, just as much as the symptoms themselves. This way of thinking about disability as a form of social injustice is known as the social model of disability.ⁱⁱⁱ

Negative attitudes, or stigma, towards people with ELCs are often associated with the following:

Invisible or non-apparent disability

Nearly 9 in 10 people with ELCs say their disability is not normally apparent to others.

Between 60% and 80% of disabilities are invisible or unseen and ELCs are just one type of invisible, or less visible disability.^{iv} Often when people think about disabled people they only think about those with a visible physical difference, as represented by 'symbols' such as a wheelchair or white cane. These stereotypes can be damaging for people with invisible, as well as visible disabilities, because those who don't conform to cultural expectations of what a disabled person looks like can have their disability called into question and their support needs rejected.

Medical uncertainty

Many ELCs are poorly understood by the medical community and can take many years to diagnose accurately. What they all have in common is that the fatigue or energy impairment at the core of these conditions cannot yet be identified or measured or differentiated in lab tests from 'normal' tiredness that a healthy individual might experience. Some conditions don't yet have a definitive diagnostic test. This means that fatigue is **medically invisible**, as well as invisible to the public view. Our society, including businesses, expects medical professionals to verify a person's disability status, based on their physiological assessment. When this cannot happen, we are left exposed to doubt and suspicion from others.



Disbelief

This double invisibility means that people with ELCs frequently face disbelief when sharing information about their health condition. Disbelief shows up as trivialising the impact of a person’s symptoms, or calling into question the extent of their disability, and even extends to expressing suspicion that the person may be exaggerating, seeking attention, or even faking their difficulties. Statements that may be intended as complementary, such as “you don’t look sick!” and “You look well!” are often experienced by people with ELCs as invalidating. Repeated encounters like these shape how individuals present and manage their disability, as well as their sense of identity and feelings of self-worth.

The impact of stigma at work

When ELCs are not understood by managers and colleagues, and the stigma of disbelief goes unchallenged, there can be negative consequences. These consequences can impact not only the individuals but also their teams, and ultimately for productivity within the whole organisation. These consequences can lead to:

- Feeling that they are not entitled to identify as disabled and that doing so involves risk
- Being less likely to share information and seek support at work for fear of being disbelieved and dismissed
- Not accessing disability support or workplace adjustments as a result of non-disclosure
- Masking difficulties at work resulting in demoralisation, burn-out and presenteeism
- Finding that working relationships with colleagues are eroded by distrust
- Pushing through symptoms at work to the point of a deterioration in health
- Taking extended periods of sickness absence
- Leaving work unnecessarily due to ill health because workplace adjustments have not been fully explored.

In the Section 4 we will explore how managers can take action to avoid these outcomes for the individuals they support at work.



4. Supporting People with ELCs at Work

Here we share with you some of our top tips for attracting, supporting and retaining people with energy limiting conditions in your organisation. For further information and support from the subject experts at Astriid see Section 5.



Effective communication

Listening and centring employees' experience and making clear that you believe them creates a safe environment for disclosure. Examples of this include:

- Asking if they have a preferred source of information about their health condition where you can find out more. This could be through a charity, support group, or social media community.
- Using a 'passport' system for agreed adjustments to reduce the burden on the employee for having to repeatedly disclose and explain their needs.



Workplace Adjustments

The key workplace adjustments for ELCs involve the time, pace and place of work. Understanding how different forms of workplace flexibility can accommodate the key features of ELCs is crucial to empowering employees to do their best work while looking after themselves. Best practice examples of this include:

- Accommodating energy limitation, including cognitive fatigue. This could involve reducing contracted hours of work and facilitating pacing strategies. Allowing employees to control their work time and schedule allows them to build time in for resting and recharging when needed and in turn, optimise their wellbeing and job performance.
- Working from home gives employees more leeway to manage fluctuating symptoms and capacity because their home environment is already adapted to this purpose.



Inclusive recruitment

To diversify the talent pool in your workforce, having a recruitment process that is accommodating of people with ELCs is essential. Examples of these measures include:

- Stating all possible flexible working provisions in every job advertisement, at the earliest opportunity so that people with ELCs can assess in advance whether the role could be suitable for their needs.
- Ensuring reasonable adjustments are in place for the application, interview, and (if applicable) performance assessment process, so that people with ELCs have the best possible opportunity to demonstrate their skills.



Managing long term sickness absence and return to work

With long-term health conditions becoming more and more prominent, it's essential that employers are equipped to handle sick leave and return to work processes. Examples of how these systems can be improved include:

- Co-producing plans for a phased return-to-work following long term sickness absence with the individual in question, tailored to their capacity and circumstances rather than following a pre-determined formula.
- Regularly evaluating progress during a return to work and extend the time period if needed. Although health may improve or stabilise during sickness absence, incomplete recovery is common with many ELCs. Be prepared to make permanent adjustments to duties, hours and location of work to accommodate a long-term health condition, and avoid pressuring individuals to get back to 'normal'.



"I am flexible with my approach to working each day depending on my energy. On bad days I prioritise the must-dos and delegate or re-shuffle my week to-do list. On good days I use time management techniques to work quickly and effectively."

"I don't schedule any meetings before 10:30 am, to give myself a buffer in case I need to take longer getting up in the morning."

Sally, digital marketing



At Astriid, we are subject experts in attracting, supporting, and retaining people with energy limiting conditions in your organisation. Is your workplace environment currently equipped to make the most of this untapped talent pool?

Here are some introductory questions for you to consider:

- Do you know how to communicate effectively and in an energy-efficient way? Do you understand the terminology around energy limiting conditions and are you aware of the common stereotypes and tropes you should avoid when communicating?
- Are the workplace adjustments you offer suitable and sufficient for people with energy limiting conditions? Do you understand how to create flexibility with the time, place, and pace at which somebody works?
- Do you know how to make your recruitment processes more inclusive? Are you equipped to how to have confident conversations about energy limiting conditions with potential new talent?
- Are you knowledgeable in how to manage long term sickness absence? Do you understand the tailored ways the return to work process should be approached for individuals with energy limiting conditions?

Being able to answer each of these questions with confidence is essential. The number of people with energy limiting conditions in the workforce is only going to continue to grow, and making changes now is the key to equipping your organisation with long-term success and meaningful inclusion.

Through Astriid's training and workshops, we offer comprehensive advice and guidance for each of these key questions. Our team is ready to work with you, so get in touch today via the details on the final page of this resource.



Working from home has been life changing. It means I don't waste energy on traveling. Before the pandemic my home life was non-existent. I would not do anything on my weekends, I would just lie on my couch to recover. Working from home saves so much energy that now I can do things with friends or family outside work, or just enjoy looking after my home.

Roberta - project manager



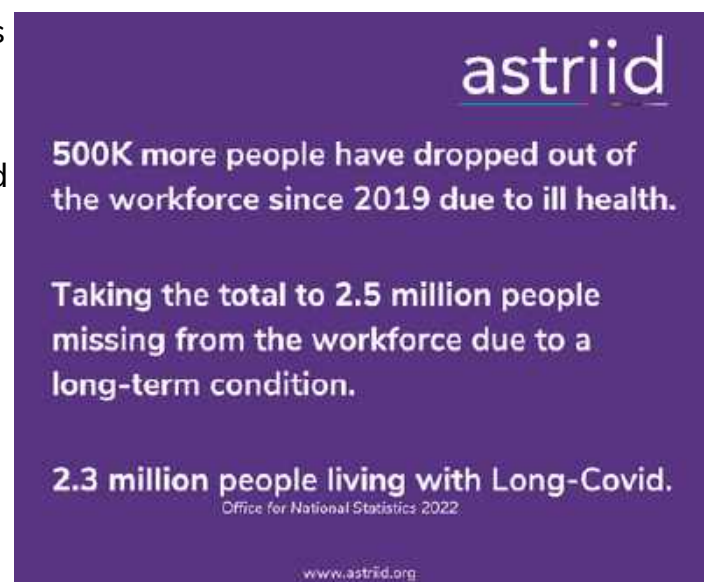
About Astriid

Astriid is a Charitable Incorporated Organisation. Our small but dedicated team consists of individuals who have all lived through the challenges of long-term health conditions and faced numerous barriers when it comes to finding employment or staying employed. **We believe that the value of work is far more than the wages paid. Employment provides routine, a sense of normality, challenges, and rewards, and when approached correctly, can also facilitate a greater sense of wellbeing.** Our late founder David Shutts found himself unable to continue working in his job when he was diagnosed with stage 4 cancer, this created a double trauma as his work provided him with meaning and purpose and losing the work he loved and facing a terminal diagnosis led him to set up Astriid.

Living with long-term conditions affects all aspects of daily life. These conditions not only affect you physically, they can also affect your mental well-being, with many suffering period of loneliness and isolation, financial strain and breakdown of relationships with partners, family and friends, as well as falling out of work due to lack of understanding. Also, energy limitations in conditions such as ME/CFS, Fibromyalgia and Long-Covid means fluctuating symptoms and energy levels, and many businesses do not understand the need for flexible hours and remote or hybrid working.

This makes workplaces inaccessible and makes people feel unemployable. It doesn't need to be this way. **We've seen first-hand that inclusive volunteering and employment opportunities really can transform the lives of individuals.**

We work to support those with long-term conditions and disabilities as well as those within a caring role across the UK by providing practical help and support with numerous resources readily available on our website and you tube channel. We currently have over 2,000 candidates signed up. **We have also launched our Training and Consultancy service that supports businesses and employers to solve the workforce challenges, and grow diversity and inclusion in the process.**



500K more people have dropped out of the workforce since 2019 due to ill health.

Taking the total to **2.5 million** people missing from the workforce due to a long-term condition.

2.3 million people living with Long-Covid.
Office for National Statistics 2022.

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Astriid Consultancy And Training

Many businesses recognise the value of having a diverse workforce, but did you know that people with long-term conditions (LTCs) form a huge untapped talent pool?

The pandemic has shown businesses that flexible working is possible, and we provide resources to help businesses do this well and dispel myths that employing people with illnesses and caring roles is bad for business. The reality is that businesses with a diverse workforce are **25% more likely to improve their bottom-line.**

People with long-term conditions offer an innovative solution to the UK skills crisis – many are highly skilled and qualified, and they’re looking for meaningful work with inclusive employers like you. The next step is to tackle the systemic barriers that are standing in-between talented individuals and the business need for their skills.

Here at Astriid, we have unrivalled expertise in long-term conditions, energy limiting conditions and inclusive employment.

We use lived experiences to shape our work, and this has led us to develop a unique set of tools to support forward-thinking leaders and managers who want to cultivate meaningful diversity and inclusion in their workforce.

We focus on:

- Attracting the best disabled talent
- Retaining your existing workforce if they develop a long-term condition
- Empowering people with long-term conditions to perform at their best

Our Training can also help and support your business into becoming **Disability Confident.**

You can hear more about our Training and Consultancy service via our **“Introducing Astriid Consulting: expertise on long-term conditions at work”** Video on YouTube by clicking [HERE](#)

You can also contact one of our consultancy team direct who will be more than happy to help:

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Unless otherwise stated, the research data in this guide is drawn from the following publications:

Astriid (2023) Making Employment Work for people with long term conditions: evidence from the frontline.

Chronic Illness Inclusion (2021) “I already have a job getting through the day”: employment, social security and social inclusion for people with energy limiting chronic illness.