

Creating Inclusive and Sustainable Employment

**Long-Term
and
Energy Limiting Conditions**

Developed by
astriid

Partnered with
 **every one**
making wellbeing personal

Introduction to Long-Term Conditions

- Long-Term Conditions are defined as a condition that cannot at present be cured but can be controlled by medication and therapies (NHS Employers, 2020)
- Long-Term Conditions can be a type of disability, but not every disabled person identifies as having a long-term condition
- When we talk about Long-Term Conditions, we are using the term to describe anybody managing a condition that has a profound effect on their life, and in particular on their ability to work

Types of Long-Term Conditions

Long-Term Conditions include (but are not limited to):

- Chronic illness e.g. ME/CFS, fibromyalgia, Long-Covid, inflammatory bowel conditions
- Some forms of mental illness e.g. depression, anxiety, PTSD
- Respiratory illness e.g. asthma, COPD, cystic fibrosis
- Some musculoskeletal issues
- Terminal illness e.g. some cancers, motor neuron disease, Parkinson's disease

Long-Term Conditions stats

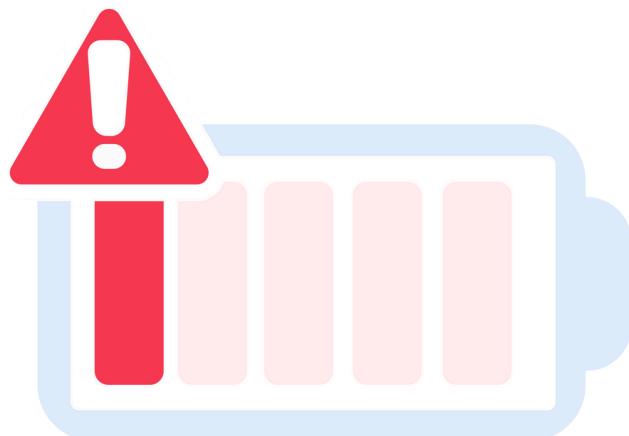
- There is an employment gap of 36% between 16-64 year olds with a work-limiting health condition and people without such conditions. (The Health Foundation, 2023)
- Between 2018-2022, the percentage of people who reported a long-lasting health condition that limits the kind of or amount of work they can do rose to 18.1%. (ONS, 2023)
- 9.1 million people in England are projected to be living with major illness by 2040, nearly 1 in 5 of the adult population. (The Health Foundation, 2023)

Introduction to Energy Limiting Conditions

- Energy limiting conditions (ELCs) are a type of Long-Term Condition
- They are often forgotten or excluded by mainstream disability programmes or support, meaning their needs are not met
- An estimated 1 in 3 disabled people are living with an energy limiting condition (Chronic Illness Inclusion, 2021)

What are Energy Limiting Conditions

- Energy Limiting Conditions are conditions where 'energy impairment' is a key feature
- They are also characterised by chronic pain and cognitive impairment
- There are often only limited treatment options for people with Energy Limiting Conditions
- People with Energy Limiting Conditions often have shared experiences of medical gaslighting
- Because they are often invisible, you may not know someone has one of these conditions
- As with Long-Term Conditions, not everybody with an Energy Limiting Condition is capable of work



Disclosure during recruitment

- Disclosure isn't always straightforward when somebody has an LTC or ELC.
- Sometimes this is due to past experiences of medical gaslighting and/or other people not believing they have an LTC.
- In other cases, people worry that disclosing their condition or communicating the impact it has on their life will negatively impact their chances of securing the role you're offering.

As a result, one of the challenges employers may face is that candidates can be worried about disclosing their condition but if candidates don't disclose then it makes it difficult for employers to know how to make their recruitment process more accessible. We've heard from previous Astriid candidates of harrowing experiences when disclosing that have damaged their confidence and put them off doing the same in the future. These instances have included recruiters changing their language and speaking to people as though they are 'stupid [or] incapable' following disclosure, being 'told by a recruiter to be careful I don't come across like I only care about the time off and the benefits', and shockingly, even one who had an employer 'who told me to try Weight Watchers' after they had disclosed their Chronic Fatigue Syndrome diagnosis. Knowing this, it is unsurprising that many capable candidates find disclosure difficult and uncomfortable – but it doesn't have to be this way.

Improving the disclosure experience

- Findings revealed that people with LTCs generally prefer to disclose their condition during interview rounds rather than on a paper application.
- Others decide whether or not to disclose 'based on the atmosphere at the interview' or first 'gauge the employer's attitude to chronic health conditions'.
- This is why it's so important to foster a supportive environment that enables confident conversations, making clear that disclosure will not impact a person's chances of securing the role. Ultimately it is the person's choice whether to disclose and if they don't feel safe, they probably won't.

Reasonable adjustments during the recruitment process

There are many reasons why somebody with a long-term condition may struggle to disclose their disability in a recruitment situation. However, reasonable adjustments should be made easy to access and request for all applicants.

Inform and ask

The more information you can provide ahead of time, the better. Let candidates know:

- The format of any activities required, including time, location, and what will be involved
- What they will be doing in each scenario e.g. specific tasks or skills tests
- That the organisation is committed to inclusion, and that reasonable adjustments are available to help the candidates perform at their best

How to make Assessment Centre days more accessible

- Instead of one full Assessment Centre day, offer to spread time out over several days
- Allow any writing tasks to be completed on a computer, or using speech to text software, to reduce energy expenditure
- Where possible, offer remote assessment tasks that people can complete from home
- Increase time limits to allow for pacing and rest breaks, and offer regular breaks in between tests and exercises
- Make sure the tests are testing what you need – is each exercise in the test useful and necessary to the role or sector at hand?

Your inclusive job advert checklist

1. Clearly state your equal opportunities policy
2. Encourage applications from marginalised groups and briefly touch on why diversity is valued by your organisation
3. If desired, reserve the role for disabled applicants only
4. Describe what flexible working options are possible in the role e.g. reduced hours or job sharing
5. Ensure you are using inclusive language and keep this specific and relevant to the job in question
6. Invite reasonable adjustments requests and clearly show the process for requesting these
7. Look at where you advertise: Many candidates at Astriid don't look for work in mainstream recruitment agencies or channels because they're looking for an employer with specific knowledge and understanding of their condition as well as their strengths. So, for example Alison, our trainer, searched for agencies that dealt with flexible and home-based working, as well as those focused on candidates with disabilities.
8. Seek out recruitment partners that specialize in matching candidates from historically excluded groups, e.g. we have a Charity partnership with a recruitment consultancy and they have been on our Supporting people workshop.



Accessible Job Ads checklist

- Make sure the platform you use is accessible, e.g. does it work with a screen reader?
- Use a font that is large enough to read and easy to comprehend.
- Offer alternative formats for applications, for example, paper forms that can be completed and returned by post as an alternative to an online form.
- Provide the contact details of someone in your organisation who can provide further information and discuss any reasonable adjustments that the applicant may need.

Communicating commitment

Ensure your commitment to recruiting people with long-term conditions is visible...

- On the Diversity section of your website
- On your careers webpage
- In your job posting if using an external agency
- In the job ad and the role profile
- On the application form



Additionally, could you provide a case study on your website or social media of someone with an LTC and how they are supported in their role?

Making & Communicating the Decision: Top tips from Astriid

- Remember, disability is the one protected characteristic you can Positively Discriminate for, but you can't use type of disability
- Remember to stick to your criteria and refer to it in your communication
- If their disability is the issue because you cannot make the adjustments, you will need to have evidence that you considered the adjustments for that specific role and why they won't work
- If they have been rejected due to accessibility issues (whether you knew or only find out after) you could encourage them to apply for other roles that could be made accessible



Developing Open Communication

One of the biggest issues with LTCs is that they can be invisible, so if an employee hasn't disclosed that they have a condition you won't know.

What stops people from disclosing they have a condition:

- Fear that they won't be believed (especially if their condition is 'invisible')
- Fear of discrimination and bullying
- Fear of stigma about being less capable and missing out on opportunities as a result
- Not wanting to be treated 'differently'
- Lack of diagnosis

The barriers above can lead to the disclosure dilemma for employees with Long-Term Conditions:

- Will the other person have enough understanding of my condition?
- How much health information should I share?
- When should I share it?
- What kinds of adjustments would be considered 'reasonable'?

The impact of stigma at work & the consequences of non-disclosure can lead to an employee:

- Masking, i.e. trying to hide their symptoms, and struggling
- Being less productive because they are struggling
- Being unable to maintain interpersonal relationships, e.g. distancing because they don't have the energy to talk or because they can't join in conversations about life outside of work
- Risking burnout leading to deterioration and inability to work

Making Workplace Adjustments

Employers have a legal duty to consider workplace adjustments for someone with a disability. Once we know someone has an LTC, we can look at what they need in order to be able to work effectively. Because everyone's experience of these conditions is different, adjustments have to be individualised. **There is no one approach to take.**

The legal position - Equality Act 2010 :

You are disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities. Long-term under the Act means expected to or has lasted more than 12 months.

Reasonable adjustments:

Reasonable adjustments are changes an employer makes to remove or reduce a disadvantage related to someone's disability. For example:

- Making changes to the workplace
- Changing someone's working arrangements
- Finding a different way to do something
- Providing equipment, services or support

What is reasonable?

The employer must consider carefully if the adjustment:

- Will remove or reduce the disadvantage – the employer should talk with the person and not make assumptions
- Is practical to make
- Is affordable
- Could harm the health and safety of others

The employer does not have to change the basic nature of the job. For example, if someone in a call centre asks for a job that does not involve taking calls, this might not be reasonable if there is no other job to give them.

An employer does not have to make adjustments that are unreasonable. However, they should still find other ways to support the disabled person. This could include making other adjustments that are reasonable.

ACAS - <https://www.acas.org.uk/reasonable-adjustments>

Types of flexible working

Working from home

Enables energy to be focused on work rather than commuting & increased stimuli.
84% in our 2023 survey needed to work from home.

Reduced hours

Allows for appointments, extra rest, etc.
49% needed to work fewer than 22.5 hours and only **17%** could work 35+.

Flexible times

Supports pacing, working when at cognitive best, and resting when needed.
Especially useful when unexpected life events occur.

Accommodating energy limitation, including cognitive fatigue:

- Reducing contracted hours of work if possible. This is often the best way to enable health management strategies of rest and pacing and rebuild work-life balance to ensure that work is sustainable in the long term.
- Remove any unnecessary energy expenditure such as commuting, navigating a busy work environment, and office social interaction. Typically, this means working mostly, or exclusively from home. Or, within the workplace, it can mean eliminating any unnecessary travel within work, providing a parking space, enabling control of the sensory environment as much as possible, including temperature, noise and light levels.
- Facilitate pacing strategies. Allowing employees to control their work time and schedule allows them to build in resting and recharging times when needed and optimise their productivity. Working from home is usually the simplest way to manage limited energy, but this can be achieved in the workplace if a quiet space for lying down and resting is provided.

Accommodating fluctuation and payback

- If working part time, spread workdays to allow rest in between
- Flexible hours within a week gives leeway to accommodate fluctuating symptoms
- Annualised hours to allow for fluctuation from one week to the next
- Disability leave – to allow for appointments,
- Redesign job, if possible, to allow for longer lead times, eliminate tight deadlines

Other adjustments:

- Resting spaces at 'work'
- Reducing travel
- Control over sensory environment, e.g. lighting; noise-cancelling headphones
- Providing information in advance
- Adapted communication styles, e.g. email rather than telephone
- Specialist IT, e.g. dictation software
- Phased job start when returning from long-term sick leave

Managing long term sickness absence and return to work

- Plans for a phased return-to-work following long term sickness absence should be coproduced with the individual and tailored to their capacity and circumstances rather than following a pre-determined formula. Evaluate progress regularly and extend the time period if needed.
- Remember that although health may improve during sickness absence, incomplete recovery is common with many LTCs. Be prepared to make permanent adjustments to duties, hours and location of work to accommodate a long-term health condition. Avoid pressuring individuals to get back to 'normal'.

Agreeing and reviewing workplace adjustments

Disabled people should feel able to approach their employer or line manager to discuss workplace adjustments. However, many people with long-term illnesses can feel afraid or nervous for asking for the things they need, for fear of stigma or discrimination.

Employers should ensure employees feel at ease to initiate a discussion about their requirements, and arrange a time to discuss workplace adjustments. From here, it's a good idea to put these things into writing, so that the employer and employee can review this later, check they are on the same page, and make any necessary alterations. For this you can use a Workplace Adjustments Passport. This can then also be used by a new manager, or if the person changes team, to understand what has been agreed with the employee and means the onus isn't on the employee to communicate what they need. There are examples online from various organisations including this one:

https://www.tuc.org.uk/sites/default/files/Reasonable_Adjustments_Disability_Passports_2019_WIP5_Model_Passport%20secure.pdf

Key points:

- Adjustments to time, pace and place of work are the most important for many LTCs (but don't assume!)
- Flexible working as a WPA is a means of creating equity
- Make sure to explore with employee what they need
- Use a passport system for continuity
- Needs may change so build in regular reviews

Creating an Inclusive Environment for People with Long-Term Conditions

It's important to create a culture of inclusion within the organisation. This is not only for those with LTCs to feel, and be, included but also for those without to understand that WPAs are a way of creating equity by enabling people with LTCs to continue in work.

Organisational culture & policies:

- Leading from the top & role models
- Making flexible working the default – build into job design & recruitment
- Inclusive hybrid working, e.g. Virtual coffee mornings
- Accessible training & networking opportunities
- Accessible events
- Help with occasional office visits, e.g. paying for taxis
- Employee Resource Groups for disabled employees
- Anonymous surveys on inclusiveness and accessibility
- Add into Diversity & Inclusion policy
- Run awareness weeks supporting relevant charities.

Key points:

- Consider how your behaviour and the messages you send out support people with LTCs
- Be prepared to think about different ways of getting work done
- Think creatively about how to include team members who are unable to attend the main workplace
- If you see opportunities within your organisation to create a more inclusive community, speak up
- Help create a culture where people with LTCs can thrive and excel at work

Additional resources, support and training

Services in and around Lincolnshire:

Long COVID Information Hub Lincolnshire connecttosupport.org

How Are You Lincolnshire haylincolnshire.co.uk

ME/Chronic Fatigue Syndrome Lincolnshire Partnership NHS Trust
lpft.nhs.uk

Support with long term conditions - steps2change Lincolnshire
lincolnshiretalkingtherapies.nhs.uk

Long Covid Support – VET lvet.co.uk

Part 2 – Long COVID & Managing Excessive Fatigue: The Project - Shine
shinelincolnshire.com

Long COVID & Physical Activity e-Learning Course - Active Lincolnshire

Workplace Training and resources from Astriid:

Resources and guides:

- [What are Energy Limiting Conditions?](#)
- Disability Disclosure - The elephant in the room
- Astriid Research Report - [Working with a Long-Term Condition](#)
- Inclusive Language Guide
- Inclusive Communications Guide

Virtual Training and Workshops:

- Inclusive Recruitment Training
- Supporting people with Long-Term Conditions in the workplace - available as a virtual group workshop or individual e-learning
- Online seminar: Inclusive language

Contact: Training@astrriid.org for more information



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