



Employer insight report

Supporting people with disabling long-term health conditions to sustain work

January 2023





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Foreword

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As someone living with a disabling long-term health condition, I'm part of a community of talented people, too many of whom are unable to access and/or sustain work.

Emma Mitchell

Talent Director, EY

As someone working in human resources, I'm part of a community of professionals dedicated to the recruitment and retention of talent. As someone living with a disabling long-term health condition, I'm part of a community of talented people, too many of whom are unable to access and/or sustain work. It's an invisible world to most.

I was therefore delighted to support the University of East Anglia and Helen Musgrove in their research to understand what works to sustain employment for people with a disabling long-term health condition. This research amplifies the experiences of many and illuminates leading organisational practices that enable organisations to retain valuable skills and experience.

There are significant organisational, economic, and human opportunities if we all do more. I believe the insights in this report clearly show the most impactful things we can do. I hope you do too!

Emma Mitchell

Talent Director, EY

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In brief

This research shows that inclusive cultures can help employees feel safe to discuss disabling, long-term health conditions at work*; this can facilitate access to the support needed to stay, and be successful, at work.

Five key drivers can enable effective support and remove systemic barriers for individuals with disabling long-term health conditions:

1.
Inclusive culture including Leadership and awareness; Respect; Enabling systems; Data and reporting

2.
Employee network providing support and advocacy

3.
Educated, empowered and supportive managers

4.
Individualised and tailored adjustments, focused on strengths

5.
Autonomy to work flexibly

We hope the insights from this research provide helpful, practical advice for senior leaders, HR professionals and line managers, especially in large organisations, and that it will also inspire conversation and further research.

** See page 5 for the definition of 'disabling long-term health condition' used for this research*



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Introduction

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You tend to find, if people feel listened to, supported, that managers have helped them overcome health barriers, they are more inclined to put in 100% and do the job well, not just for themselves but for you and for the team ...

Line manager

33%

of employees with a long-term health condition have not discussed it with their employer

131 million

days are lost each year to sickness absence in the UK

2.5 million

working-age adults out of the UK labour market because of long-term sickness (up from 2 million since 2019)



Before the COVID-19 pandemic, there were 7.5 million working-age people with a disabling long-term health condition in the UK, and this number was set to rise¹. Following the COVID-19 pandemic, an estimated 2.3m people in the UK are now living with Long Covid including 342,000 whose ability to undertake day-to-day activities has been “limited a lot”². Indeed, the number of working-age adults who are out of the labour market because of long-term sickness has been rising since 2019, from around 2 million people in spring 2019, to about 2.5 million in summer 2022.³

Health and ill-health is a universal feature of being human, and evidence suggests that work can be good for health as well as social inclusion⁴. However, individuals with a disabling long-term health condition are too often unable to find or sustain employment. The employment rate for disabled people of working age is only 51.3%, compared to 81.6% for those with a non-disabling health condition and 81.2% for those with no health condition⁵. 33% of employees with a long-term health condition have not discussed it with their employer⁶. This may be for a variety of reasons, including fear of discrimination⁷.

Yet providing effective workplace support to individuals with health conditions can bring a range of benefits⁸⁹ including employee health, wellbeing, engagement, and performance, and organisational retention, engagement, representation, and reputation. There’s also value to the wider economy – some 131 million days are lost each year to sickness absence in the UK, and the combined annual cost to the economy from worklessness and sickness absence is approximately £100 billion¹⁰.

1 Public Health England (2019) Health Matters: Health and Work. London: TSO.

2 Office for National Statistics (2022) Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 6 October 2022.

3 Office for National Statistics (2022) Half a million more people are out of the labour force because of long-term sickness: 10 November 2022

4 Waddell, G., & Burton, A. (2006). *Is Work Good for Your Health and Well-Being?* London: TSO.

5 Public Health England (2019) Health Matters: Health and Work. Crown Copyright.

6 Public Health England (2019) Health Matters: Health and Work. London: TSO.

7 Hemming, S., McDermott, H., Munir, F., & Burton, K. (2021). Employer perspectives concerning the self-management support needs of workers with long-term health conditions. *International Journal of Workplace Health Management*.

8 What Works Centre for Wellbeing (2017) *Why Invest in Employee Wellbeing?* www.whatworkswellbeing.org

9 Department for Work and Pensions (2020) *Employing disabled people and people with health conditions* www.gov.uk.

10 Public Health England (2019) Health Matters: Health and Work. London: TSO.

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Using research to better understand what works

Our motivation to learn and develop new ways of creating inclusive workspaces reflects EY's purpose of "building a better working world". We have therefore supported the University of East Anglia on this qualitative research project in the UK to explore what employers can do to support individuals with a disabling long-term health condition to stay in work.

One-to-one interviews were conducted in four large organisations from banking, consumer goods, technology, and further education sectors. Interviews were conducted with four HR professionals, eight line-managers and nine employees with disabling long-term health conditions. Health conditions were typically invisible and fluctuating, and included mental health, energy-limiting, digestive, gynaecological, musculoskeletal and neurological conditions. With the exception of further education, work was typically desk-based; some roles were customer-facing.

The research focuses on individuals with a disabling long-term health condition because this is where an employment gap remains. In this context, 'disabling' means that a physical or mental impairment has a substantial and long-term adverse impact on the individual's ability to carry out normal day to day activities¹¹. Long-term means that the condition is expected to last at least 12 months¹². It is recognised that identity and language is very personal and not all individuals meeting this definition will choose to identify as disabled.

¹¹ Equality Act, 2010

¹² Office for National Statistics

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The five key drivers



The research identified five key drivers that can enable effective support and remove systemic barriers for individuals with disabling long-term health conditions, together with positive individual and organisational outcomes (see Figure 1).

1

Inclusive culture

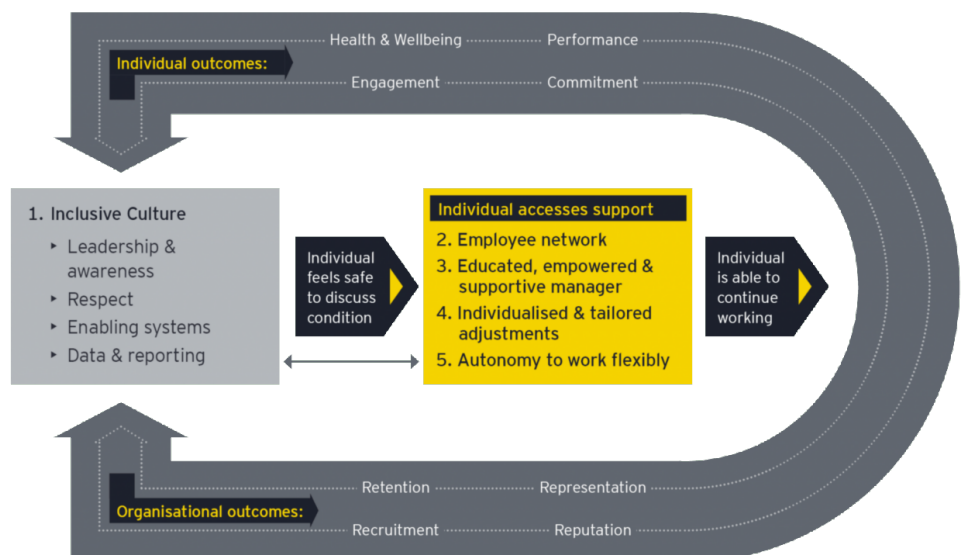
An inclusive workplace culture creates a sense of belonging for all employees, values differences and removes barriers which prevent equal outcomes. It plays a significant role in creating psychological safety – the ability to show oneself without fear of negative consequences for career or treatment within the organisation – which can influence an employee’s decision about whether to discuss their health condition at work. This decision should always be a personal choice, and even in the most inclusive cultures some people will decide not to do so.

Where employees do choose to discuss how their condition affects them at work, it opens a vital channel of two-way communication, and they are better able to access the support needed to sustain work and performance and mitigate potential adverse consequences of work on their health. This can also help to increase colleagues’ awareness of, and challenge misconceptions about, people with long-term health conditions which in turn tackles stigma and improves support.

Critical features of an inclusive culture, in the context of disabling long-term health conditions, include:

- ▶ **Leadership and awareness** Positive attitudes about people with disabling long-term health conditions need to be championed by leaders if they are to filter down through the organisation, and behaviours and actions must be consistent with rhetoric to be seen as genuine. Examples include:
 - ▶ Treating disability and health as a mainstream business issue, setting clear expectations around support for, and value of, individuals with disabling health conditions.
 - ▶ Role modelling and enabling positive practices, e.g., flexible working.
 - ▶ Maintaining a dialogue with employees around disability including disabling health conditions.
 - ▶ Lending explicit support to awareness raising activities, including sharing personal stories if relevant.
- ▶ **Respect** Individuals with disabling long-term health conditions should feel heard, believed, respected and valued for their contribution by their managers, colleagues and leaders.
- ▶ **Enabling systems** The barriers facing people with disabling long-term health conditions should be considered in wider organisational systems, (e.g., recruitment, assessment, working practices, absence management and the physical environment). Systems should not only enable people to self-manage health

Figure 1: Drivers and benefits of work sustainment for individuals with a disabling long-term health condition



conditions at work, but also enable them to succeed. Policies and processes should be flexible, with changes informed by employee feedback. Systems and practices should align to messaging – for example, an overly aggressive focus on short-term targets and a culture of presenteeism are likely to undermine effective support.

- ▶ **Data and reporting** Gathering data on i) the prevalence and experiences of individuals with health conditions, ii) disclosure rates, iii) impact of interventions, and iv) recruitment, performance, and progression, can help employers to make the case for action, support employees effectively and address discrimination.

2

Employee network providing support and advocacy

An employee network provides a safe space for individuals to access support from colleagues with similar lived experiences. It also helps to increase understanding within the organisation, providing a forum for consulting employees on their experiences, organisational change, and policies and processes that may affect them. Networks can also provide a platform to raise awareness and share stories with colleagues which can change attitudes and unlock practical and emotional support. Employees should be given time to participate and recognised for their contribution. Such forums should work in partnership with, and not replace, professional HR services.

“

I would say it's very open, from all aspects really. I feel safe and comfortable to share my experience and share my condition ... it's definitely the sort of culture that enables you and empowers you to do that, which I think is important.

Employee





3

Educated, empowered and supportive managers

Managers have a critical role in supporting employees with disabling long-term health conditions, and ensuring positive attitudes filter down to teams and colleagues. Effective managers make individuals feel safe and valued. They are empathetic, flexible, listen to and follow up on actions, support job crafting, check in regularly but respect privacy, and provide additional support and feedback when needed without micromanaging or making capability assumptions.

Allowing some managerial discretion (e.g., in how to implement adjustments and absence management policies) can help tailor support to the employee's particular circumstances. They need to feel empowered to work collaboratively with employees, to adapt roles and working arrangements to play to individual strengths and mitigate risks.

However, managers need relevant training to understand organisational values, relevant policies and practices and ensure that they have the confidence and tools to provide effective support. This will help them avoid incorrect assumptions about support requirements and capabilities and engage constructively with employees. They can also benefit from the support of a known and trusted partner in HR.

“

I don't think that people who've got long-term conditions would want to have any lesser performance expectations from the next person. They wouldn't want to have lesser career ambitions, they want to still do a good job, they want to be able to deliver in their role. But how they get there will be different ...

HR Representative

Managers should also support the individual to discuss with colleagues how their condition impacts them at work, if they wish to do so. Where team members understand their colleague's situation, and act in accordance with organisational values, they can be an important source of emotional and practical support.

4

Individualized and tailored adjustments, focused on strengths

Each individual and how their condition affects them at work is unique – there is no one size fits all in terms of the support required to sustain work. To achieve fairness and equity in terms of outcomes (and to comply with the Equality Act, 2010) it is necessary to tailor support and adjustments to people's individual circumstances.

Useful adjustments can include employee-led job crafting, where the role is adjusted to align with strengths and mitigate risks to health; changes to tasks; coaching; prompt access to specialist equipment and adaptations to the work environment. Access to employer-funded support, (e.g., through an employee assistance programme, private medical appointments), can also be useful for some individuals, although it is important that employers are not seen to be outsourcing their responsibilities.

Adjustments to performance expectations or alternative roles may sometimes be appropriate, but employers should avoid making assumptions about capability, and where possible focus on support that enables an individual to perform within their current role.



I feel valued, I'm still good at my job, I make a difference in people's lives and I'm allowed that opportunity to do it. So by working from home, having access to these different services and tools, it helps me be the best version of me regardless of what's happening with my condition ... I feel as if it makes me work harder, it makes me want to give even more of myself to my company, because they've given so much to me, and they appreciate me for who I am.

Employee

5

Autonomy to work flexibly

Autonomy to work flexibly, to reduce hours and/or work from home can be important in supporting work sustainment in professions where this is feasible. It is important both practically (in terms of condition self-management at work) and psychologically (in terms of the trust and control given to the individual). Employers should ensure that autonomy to work flexibly is accompanied by realistic performance expectations and regular contact with an individual's manager and colleagues, to mitigate potential risks of excessive hours (to compensate for fluctuating capacity) and isolation from colleagues.

The COVID-19 pandemic has increased acceptance, ease, and prevalence of flexible working in many organisations. This has increased opportunities for individuals with disabling health conditions to access a wider range of roles, whilst managing their condition effectively. It is important this flexibility is sustained.

6

Conclusion



This study builds on existing research to highlight an issue which is more important than ever. There is huge opportunity to do more, with potential benefits for both individuals and organisations¹³.

Employers can realise these benefits by taking action around the five key drivers:

- 1.**
Inclusive culture including Leadership and awareness; Respect; Enabling systems; Data and reporting
- 2.**
Employee network providing support and advocacy
- 3.**
Educated, empowered and supportive managers
- 4.**
Individualised and tailored adjustments, focused on strengths
- 5.**
Autonomy to work flexibly

With thanks

Thank you to all organisations and participants without whose support, time, openness and sometimes vulnerability, the research would not have been possible.

About Helen Musgrove

Helen Musgrove conducted this research as part of her post graduate studies in Organisational Psychology at the University of East Anglia. She is currently the Director of Psychological Consulting at a neurodiversity consultancy, following a twenty-year career as a leader in the Civil Service, focused on addressing some of the UK's biggest social policy challenges. She is passionate about inclusion of people with disabling long-term health conditions, having spent nearly a decade as the senior champion for mental health at the Department for Digital, Culture, Media and Sport.

¹³ Hemming, S., McDermott, H., Munir, F., & Burton, K. (2021). Employer perspectives concerning the self-management support needs of workers with long-term health conditions. *International Journal of Workplace Health Management*

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