

abbvie

# Working Well

Creating workplace cultures to unlock the full capabilities of Australians living with chronic health conditions.

People.  
Passion.  
Possibilities.®

# Foreword



**Deidre Mackechnie, Executive Officer,  
Australian Patient Advocacy Alliance**

I'm delighted that AbbVie has gathered insights from Australians on the important issue of supporting people living with chronic health conditions to actively participate in the workforce. It is so important to give a voice to those people with chronic health conditions on what is needed given that one in two Australians are living with at least one chronic health condition.<sup>1</sup>

While many individual patient advocacy organisations do provide guidance for employees and employers on disclosure and best workplace practice, it is something we all really need to address and act upon – not just the Australian Patient Advocacy Alliance as an umbrella organisation, but also employers, businesses, Government and society as a whole.

I recently attended an international conference on obesity and one of the three pillars was on workforce participation. What is becoming very clear is that supporting people with chronic conditions in the workplace to enable them to participate meaningfully is simply good workforce practice.

It is not just about being an empathetic employer, it is about doing everything we can to maximise workforce participation, particularly when there may be significant workforce shortages in many sectors such as healthcare and aged care. Maximising workforce participation is where we really need to be placing emphasis to get engagement on this issue of supporting individuals with chronic health conditions with businesses, employers and with Government.

We need to put measures in place for individuals with chronic conditions for many reasons – as they need to support themselves and maybe a family financially, they need to feel they are participating in society and have a sense of worth. But from a community, employer and government perspective, we really need to provide support in order to be able to meet current and future workforce needs.

This report highlights some important areas that need attention and I look forward to working with AbbVie and other organisations to take this further.

It's not just an individual issue. It's an employer issue, it's a government issue and a community issue.





**Nathalie McNeil, Vice President and General Manager of AbbVie Australia & New Zealand**

In today's dynamic and challenging workplace environment, the need for inclusivity and support for all employees has never been more crucial.

AbbVie in Australia has long been recognised by Great Place To Work Best Workplaces list, and in our continual pursuit of excellence, we have chosen to highlight the challenges faced by Australian employees living with chronic health conditions. Why?

Because we are committed to diversity and inclusion and want to better support our patients, our employees and our communities.

*The Working Well Report – Creating Workplace Cultures to Unlock the Full Capabilities of Australians Living with Chronic Health Conditions* delves into the experiences and challenges faced by these employees, exploring their decisions related to disclosing

the impact on their career progression. It also brings forward the wider attitudes prevalent in today's workplaces and identifies key opportunities for enhancing education and support measures.

This Report is more than just a compilation of data. It's designed to spark conversation and help motivate employers throughout Australia to create more inclusive and supportive workplaces for all, so that each Australian can reach their full potential.

## Acknowledgements

*AbbVie acknowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders past and present.*

Thank you to the people living with chronic conditions who took part in our focus group, the consumers who responded to our survey and the following organisations who assisted in the research and development of this report:

- The Brain Foundation
- Crohn's & Colitis Australia
- Black Dog Institute
- Arthritis Australia
- Diabetes Australia
- Rare Cancers
- Hospital Research Group
- Australian Patient Advocacy Alliance
- Australian Patients Association

# About this Report

Chronic health conditions are defined by the Australian Institute of Health and Welfare as long lasting conditions with persistent effects.<sup>2</sup>

As well as their health impact, the social and economic consequences of chronic health conditions can impact peoples' quality of life. They are becoming increasingly common in Australia and many people are living with two or more chronic conditions at the same time.<sup>2</sup>

In 2022, the National Health survey uncovered that eight in 10 Australians (81.1%) had at least one long-term health condition, and half (49.9%) had at least one chronic condition.<sup>1</sup> Mental health and behavioural conditions (26.1%), back problems (15.7%), and arthritis (14.5%) were the most common chronic conditions.<sup>1</sup>



# Prevalent chronic conditions experienced in Australia in 2022:<sup>1</sup>



**26.1%**

Mental and behavioural conditions



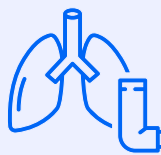
**15.7%**

Back problems



**14.5%**

Arthritis



**10.8%**

Asthma



**5.3%**

Diabetes



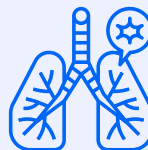
**5.2%**

Heart, stroke and vascular disease



**3.4%**

Osteoporosis



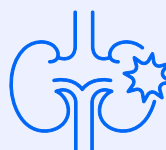
**2.5%**

Chronic obstructive pulmonary disease (COPD)



**1.8%**

Cancer



**1%**

Kidney disease



Whilst data is available on the prevalence of chronic conditions in Australia, there is a lack of information on the prevalence of chronic conditions in Australian workplaces, how the participation and progression of people living with chronic condition/s are impacted and what support is available or needed for them to realise their full potential.

The *State of the Future of Work 2023* report found that since the COVID-19 pandemic, poor mental health outcomes have increased particularly amongst those with a chronic illness, as well as among young and middle-aged workers and caregivers.<sup>3</sup>

The report found that workers with a chronic condition are faring worse than their healthy colleagues and most highlight that work has become harder for them since the pandemic. Almost half of those with a chronic condition in the report feel less motivated about their work with fewer opportunities for advancement. Two-thirds of those with a chronic illness feel exhausted. Half (almost 54%) of those with a chronic illness report working harder at their jobs and 37% report having less time to complete work tasks.<sup>4</sup>

A University of Melbourne 2023 study also delved into the issues around disclosure of chronic illnesses in the workplace amongst leaders and managers. The leaders surveyed were from different management positions from executive, senior, middle to lower management and frontline leaders from different organisations and industries in Australia and New Zealand. It found that leaders were more likely to partially disclose their illness (54%), with just over a quarter of leaders revealing little or nothing about their chronic illness to their employer (28%), and only 18% of leaders fully disclosing their illness in the workplace.<sup>4</sup>

**54%** of leaders were more likely to **partially disclose their illness**<sup>4</sup>

**28%** of leaders **reveal little or nothing about their chronic illness** to their employer<sup>4</sup>

**18%** of leaders **fully disclose their illness** in the workplace<sup>4</sup>

A University of Melbourne 2023 study using Australian Census data indicates that managers **make up 38% of the workforce** who have been diagnosed with a chronic health condition.<sup>4</sup>

# Methodology

This *Working Well Report – Creating Workplace Cultures to Unlock the Full Capabilities of Australians Living with Chronic Health Conditions* draws on a number of reference points and insights to gain further understanding of the current situation and needs. We sought insights from individual people with chronic conditions in the workplace and patient advocacy groups. We conducted research into the experience of Australian workers with chronic health conditions and how they manage their condition; how their colleagues are approaching and supporting people with chronic health conditions; and where the opportunities lie to improve or introduce workplace education and supportive measures.

**1. Desktop research** to uncover issues that may have been raised publicly in recent years as well as any published papers about workplace experiences of people living with chronic health conditions, existing materials for workplaces from patient advocacy groups and existing guidelines. Findings from this were used to help inform the other research approaches as well as the content of this report.

## 2. Qualitative interviews with representatives from various patient advocacy groups

representing eight chronic condition groups, to gather insights on their lived experiences and best practice when it comes to workplaces for people living with chronic conditions.

**3. A patient focus group** to hear personal experiences and gain further insights from six patients living with a chronic condition/s in the workforce.

The above research and interviews helped inform the topics and questions for a large scale robust, quantitative consumer survey.

**4. A quantitative consumer survey** of first-hand experiences of 1,000 Australians within the workplace to explore their knowledge, understanding and experiences with chronic condition/s in the workplace.

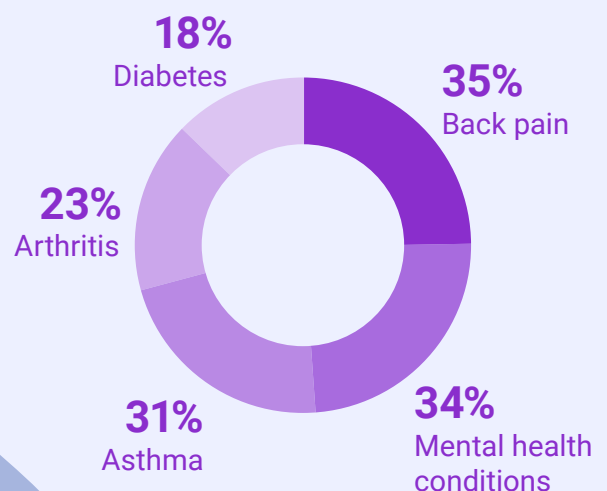
The *Chronic Health Conditions in the Workplace 2024* survey was undertaken by research firm McCrindle on behalf of AbbVie Australia to obtain quantitative data through an online survey in July 2024 of 1,000 Australian workers in organisations with five or more employees.<sup>5</sup>

*The Chronic Health Conditions in the Workplace 2024* survey reported the most frequent place of work was across a wide range of places. **One quarter most frequently working in an office building.**

Followed by retail, educational institutes, healthcare facilities, from home, construction sites, hospitality, transportation and warehouses.<sup>5</sup>



**Two in five Australian workers (39%)** are living with a chronic condition.<sup>5</sup>



# Executive Summary

The following contains a summary of the findings of each of the key research elements.

## Qualitative interviews with patient advocacy groups

Patient advocacy groups are not for profit organisations that seek to support the interests of healthcare consumers, their families and carers. These organisations generally promote views that are independent of the government, the pharmaceutical industry and healthcare providers.

The qualitative interviews with representatives from various patient advocacy groups representing eight chronic condition groups uncovered the following key themes:

### Disclosure

- Based on the environment and culture within a workplace, individuals may not disclose their medical conditions to their manager or employer for fear of losing their job or having their role reduced.
- The choice to disclose a condition should be entirely up to the individual unless it directly impacts their ability to perform job tasks or their safety. A potential risk to an individual's safety can be critical in this decision, for example in sectors where individuals are expected to do physical labour as part of their job.
- People are more likely to disclose if they feel that their employer is going to 'make reasonable adjustments' or accommodate their needs.
- People avoid disclosure of their mental health conditions due to fear of stigma and discrimination.

- The embarrassment surrounding conditions such as Crohn's disease and ulcerative colitis can be difficult to deal with and become a reason individuals do not disclose their condition.
- Once the individual has disclosed their condition, it is important for the employer/manager to ask the individual how the company and co-workers can support them to ensure the individual feels more in control as well as providing guidance to co-workers and employers.

### Stigma and discrimination

- There is less empathy and understanding towards people with chronic conditions because you cannot "see" them.
- One of the main reasons that people contact Diabetes Australia is for advice regarding discrimination within the workplace and to understand their rights.
- As arthritis is a non-visible condition, there is a lack of understanding about why individuals need to take additional sick days or need adjustments made for them at work and this can lead to increased discrimination from peers.
- There is a perception that individuals living with chronic migraines and headaches have a poor work ethic when they need to take time off work due to their condition.

There is less empathy and understanding towards people with chronic conditions because **you cannot "see" them.**

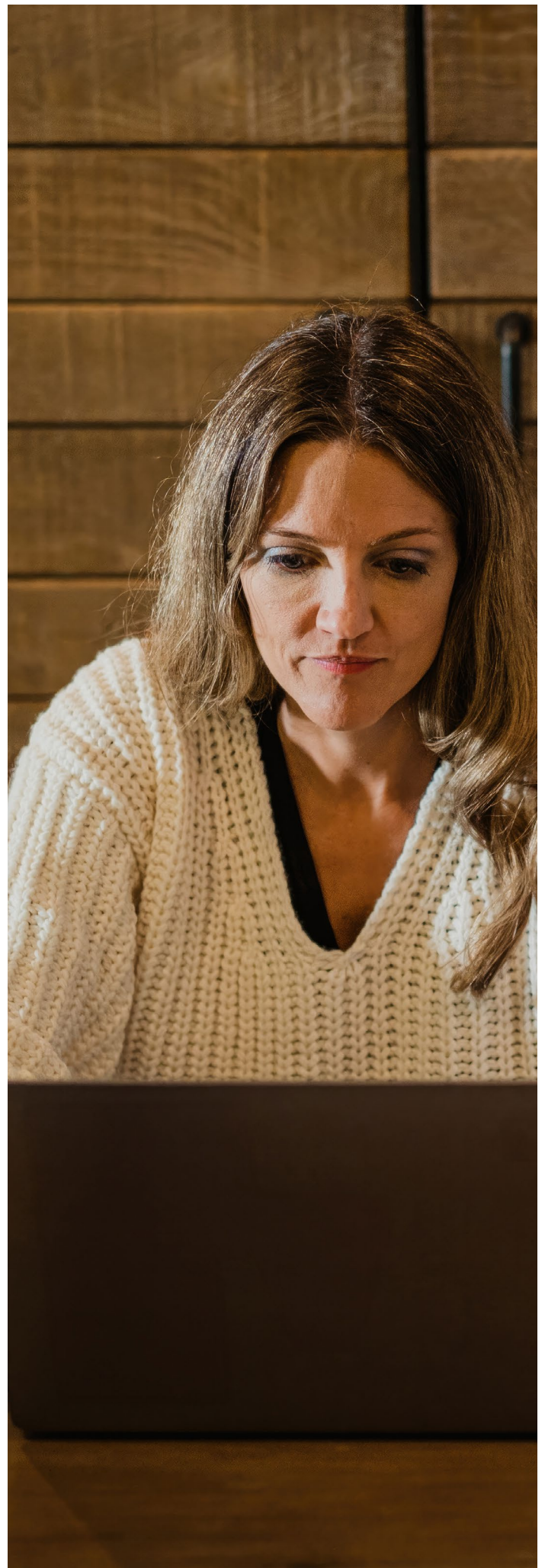


## Career planning and progression

- The biggest limitation for career progression can sometimes be from those living with chronic conditions themselves. Employers and organisations can play a major role to help individuals feel confident to seek help when it is needed without fear of being punished.
- Arthritis has a significant impact on individuals' mental health. This is exacerbated when those living with arthritis feel as if they are forced out of the workforce or cannot progress in their careers.
- Anxiety is one of the biggest symptoms of Parkinson's disease and can become a massive barrier for individuals in the workforce, who are often capable of completing their tasks but their anxiety and workplace pressures stop them from doing so.
- Crohn's disease and ulcerative colitis are most commonly diagnosed between the ages of 15 to 30 years<sup>6,7</sup> – usually when people are starting their careers. Career planning, the ability to progress and take up new opportunities depends on an individual's health status, including their symptoms and flare ups.

## Workplace education

- Education in the workplace is needed to increase understanding about common chronic diseases that can also have an impact on mental health.
- There is a need to educate and address stereotypes or misperceptions about some chronic conditions. For example, that arthritis doesn't only impact the employees who are over the age of 65 years. Parkinson's disease presents different symptoms and has a different trajectory for each patient. Due to a lack of awareness and education, people can make judgements that can lead to stigma and discrimination.
- Individuals being able to share their personal stories within the workplace is a great way to start a conversation and highlight the challenges those living with chronic conditions are facing.



## Patient focus group

The patient focus group with six individuals living with chronic conditions in the workforce highlighted the following factors important from a lived experience point of view:

- The experiences of those who disclose their condition can significantly vary depending on their workplace. People living with multiple chronic conditions may only want to disclose the condition that is currently impacting them the most. The reluctance to disclose a chronic condition may be caused by embarrassment, or fear of being discriminated against.
- Flexible work arrangements, where individuals are able to work from home (or leave work for appointments), greatly improves their ability to manage their symptoms.
- Career progress and opportunities can be limited as some individuals would rather stay in a safe and positive environment than take a risk - even if they know they are capable of doing more in the workplace. Negative experiences from previous workplaces and environments can influence individuals' likelihood of taking career progression and opportunities in the future.





## Sasha's story

Sasha Simon now feels comfortable being 'loud and proud' about her chronic condition in the workplace. She has been working in marketing in the medical devices industry for more than a decade, and was diagnosed with ankylosing spondylitis when she was a university student.

"I've always been very open about my condition but I don't tend to bring it up in an interview setting," she says. "I guess there's a stigma around having a chronic condition and how difficult that could be to manage in an employee."

"However very early on in starting in a role I do disclose my condition and I'm very open about my medical information."

"I think for the most part, people are compassionate and caring. Once they have a bit more understanding of what you're going through, they're more lenient in terms of their attitudes towards you. Everyone's entitled to whatever privacy they choose, particularly with medical information being so highly confidential, so I also tell my team as well as my manager because I found by sharing my information, people tend to respond positively."

While a big part of Sasha's job is desk-based, a significant part requires going into hospitals. Being immunocompromised means she needs to be very aware of hand hygiene and hygienic controls when she visits hospitals.

She also needs to make sure she follows a routine of stretches to avoid becoming extremely stiff by the end of the day. "When I'm in an office, I tend to do it in the bathroom which means a moderated form of the exercises. I'm lucky in that I've got flexibility to work from home."

Sasha says being pregnant has brought a number of different challenges and an increase in medical appointments, needing extra time off work and flexibility.

"Because I'm pregnant, with my condition everything becomes a bit more critical, a bit more high risk, a bit more need to fix it now," she says. "Even though I know there's the right mechanisms in place to have the time off, I have found from a personal level with managers and colleagues that I've had to share more information than I probably would be comfortable with, just for a bit more understanding."

Sasha is keen to apply her experience to benefit others and is on an external workplace committee that is trying to create awareness of disability in the workplace.

"I think there definitely needs to be more education overall. This should cover both living and working with a chronic condition and on managing someone with their chronic condition. Also, what your rights are as an employee with a chronic condition because I think for a lot of people that is quite unknown."

Her goal for people with chronic conditions is for them to feel proud of who they are, safe emotionally and physically, and safe to be their authentic selves in the workplace.

"Believe in yourself, trust in yourself and give yourself the patience and time to get through each challenge," she advises. "It's a process."

# Chronic Health Conditions in the Workplace 2024

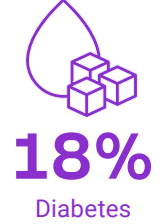
The Chronic Health Conditions in the Workplace 2024 quantitative survey found:<sup>5</sup>

Chronic health conditions, unsurprisingly, have a significant impact on Australians at work.

**Two in five Australian workers (39%)** are living with a chronic condition.



The most common conditions are:

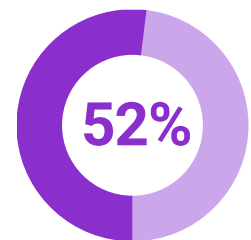


**Almost half of Australian workers (48%)** are aware of at least one co-worker living with a chronic health condition.

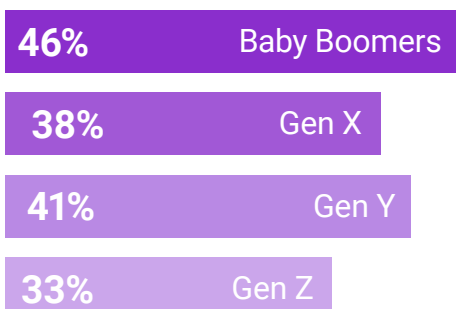
The conditions these workers are most aware of are:



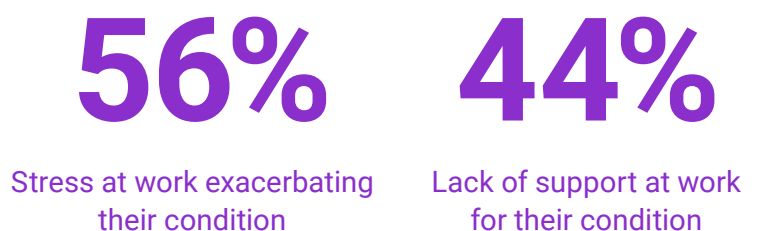
Half (52%) of those with a chronic condition are not applying for a position or pursuing a career opportunity because of their condition.



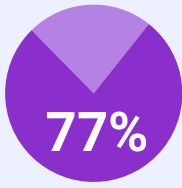
Older workers are more likely to be living with a chronic condition:



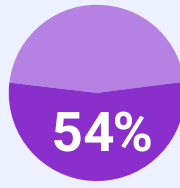
One in three (37%) workers with a chronic condition have left a job due to their condition. The most common contributors to this decision are:



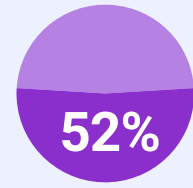
Those living with chronic conditions can face discrimination and stigma at work.



of Australian workers believe individuals living with a chronic condition **experience discrimination and stigma in the workplace**

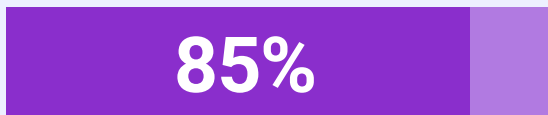


of Australian workers **don't disclose having a chronic condition** due to fear of discrimination and stigma



of Australian workers believe a chronic condition could **hinder their career progression and opportunities** for advancement

There is strong support in the workforce for opportunities to be provided for those with a chronic condition.



of Australian workers overwhelmingly believe strongly or somewhat that it is important for **people with a chronic health condition to have opportunities to stay in the workforce.**

Australian workers believe more can be done to support people with chronic conditions in the workplace.



**Three in five workers** strongly or somewhat agree their workplace could be making more reasonable conditions of work and physical/environmental adjustments for people



**Just one in five (22%)** have received education in their workplace



Meanwhile **more than four in five (83%)** want training to learn how to better support individuals living with a chronic condition at work



**One in three workers in organisations (37%)** manage an employee with a chronic condition



Yet only **three in five of these managers (58%)** feel extremely or very well equipped to manage an employee with a chronic condition



**A third (32%) of workers** with a chronic health condition are most likely to go to their manager for support at work



However **18% said there was no person or place to go to for support** in their workplace

The key areas to improve are:

**67%**

Flexible working hours

**63%**

Support to take time for medical appointments or treatments

**57%**

Workplace policies to support individuals

# Key Themes

## Disclosing your chronic health condition to an employer

Whether to disclose a chronic health condition to an employer and/or work colleagues is something that will no doubt be on the mind of a person with such a condition when starting a new job or when they have been newly diagnosed.

Almost half of all Australian workers (48%) who responded to *The Chronic Health Conditions in the Workplace 2024* survey believe they would be extremely or very likely to disclose a condition to their employer if they were living with a chronic condition.<sup>5</sup> Breaking this down by whether the person has a chronic condition or not, there is still a similar likelihood to disclose – 47% of those with a chronic condition saying yes they would versus 50% for those who don't have a chronic condition.<sup>5</sup> Only 10% of workers with a chronic health condition had not disclosed their condition to anyone in their workplace.<sup>5</sup>

On the other hand, this also highlights that half of Australians overall, regardless of whether living with a chronic condition or not, would not be likely to disclose this to their employer.<sup>5</sup>

Australian workers who were surveyed believe the barriers to disclosure are fear of discrimination (54%), a concern it might hinder their career progression and opportunities for advancement (52%) and a belief that health conditions are a personal matter (47%).<sup>5</sup>

Participants in our patient focus group meeting raised that individuals who do disclose their chronic condition can help

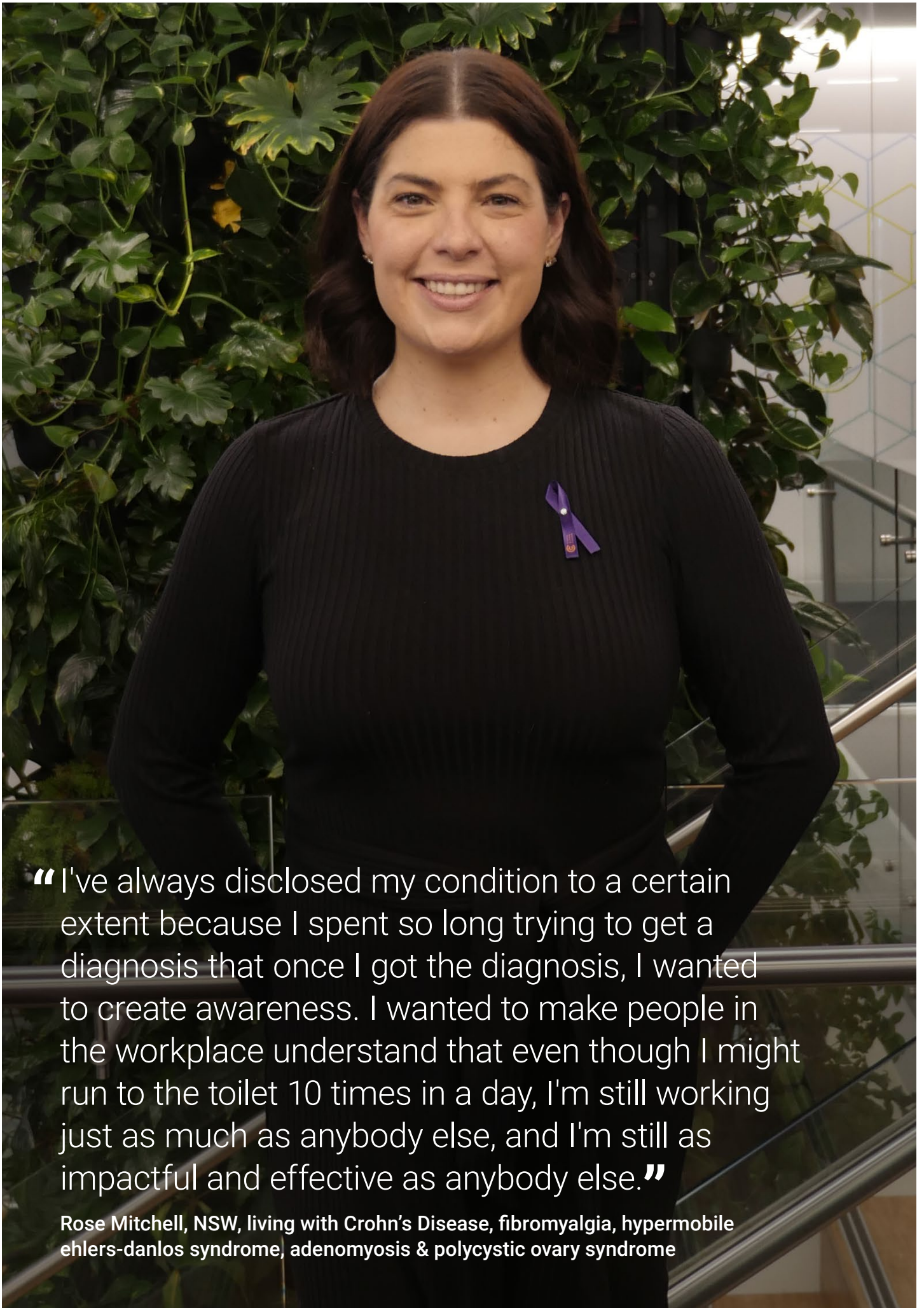
facilitate understanding between themselves, their colleagues and/or their employees and employers. However, individuals' experiences of disclosing their condition can significantly vary depending on their workplace.

Due to considerations that need to be put in place, sometimes employees disclose their condition because they feel they have no other choice.

People living with multiple chronic conditions may only disclose the one that is currently impacting them the most, rather than mentioning everything they are living with at once. Individuals' past negative experiences of disclosing their condition can also make them hesitant about disclosing their condition to future employers.<sup>4</sup>

Research on leaders in the workforce living with chronic health conditions found that leaders were more likely to just partially disclose their condition (54%), with a little over a quarter (28%) choosing to say little or nothing to their employer.<sup>4</sup> Leaders were more likely to disclose their condition to their supervisors but were reluctant to communicate the extent of the impact of the chronic illness.<sup>4</sup>

The leaders were concerned that disclosing their condition could have a negative impact on their career. The report noted that the reluctance to disclose a condition can be higher with leaders, partly because of their prominence in an organisation and the accountability that comes with their leadership roles.<sup>4</sup>



“ I've always disclosed my condition to a certain extent because I spent so long trying to get a diagnosis that once I got the diagnosis, I wanted to create awareness. I wanted to make people in the workplace understand that even though I might run to the toilet 10 times in a day, I'm still working just as much as anybody else, and I'm still as impactful and effective as anybody else.”

**Rose Mitchell, NSW, living with Crohn's Disease, fibromyalgia, hypermobile ehlers-danlos syndrome, adenomyosis & polycystic ovary syndrome**

“Crohn’s & Colitis Australia encourages individuals to make their own assessment on whether they want to disclose their condition to their employer and if they feel safe to disclose to their employer. People are more likely to disclose if they feel like their employer is going to ‘make reasonable adjustments’ or accommodate their needs.”

**Leanne Raven, CEO of Crohn’s & Colitis Australia**



“Increased understanding of arthritis will reduce individuals' reluctance to disclose their condition. However, the choice to disclose a condition should be entirely up to the individual unless it directly impacts on their ability to perform the tasks of the role.”

**Jonathan Smithers, CEO of Arthritis Australia**



“Often I feel disclosing my condition may hinder my career growth as I am likely to be cut off from some projects.”

**Anonymous research participant:  
Male, aged 64, construction site manager,  
NSW, living with chronic back pain**

Taryn Black, Chief of Strategy at Diabetes Australia says it is a matter of personal choice as to whether a person with diabetes discloses their condition to their employer.

“If a person feels comfortable, open and transparent communication right from the outset can be beneficial for both parties where a person feels safe to disclose. This is so that the employer understands that the person has diabetes, and there's an agreement about what reasonable adjustments might be needed. Employers are obliged to make reasonable adjustments in the workplace unless this results in an ‘unjustifiable hardship’ (usually cost) to their business.”

**Taryn Black, Chief of Strategy at Diabetes Australia**

# Stigma and discrimination

“We're seen as a liability - that's the plain and honest truth - by uneducated people and organisations. We are seen as a liability even in educated organisations.” Rose Mitchell, NSW, living with Crohn's disease, fibromyalgia, hypermobile ehlers-danlos syndrome, adenomyosis & polycystic ovary syndrome.

In Australia, Commonwealth and State laws (Disability Discrimination Act 1992 and Fair Work Act 2009) make discriminating against, harassing or victimising people with disabilities unlawful.<sup>4,8,9</sup> Yet people living with chronic health conditions may be unaware of this and may be fearful of how they might be regarded and treated should they disclose their condition to their employer and colleagues.

*The Chronic Health Conditions in the Workplace 2024* survey found that three in four Australian workers (77%) definitely or somewhat believe individuals living with a chronic condition experience stigma and discrimination in the workplace.<sup>5</sup>

In addition, more than half (54%) of Australian workers believe one of the barriers to disclosing a chronic condition is fear of discrimination.<sup>5</sup>

Chronic health conditions require ongoing management, may involve episodic flares and may be associated with comorbidities that make the condition more complex to manage. A chronic condition may become more 'enmeshed with an individual worker's identity, making it more challenging to negotiate in the workplace'.<sup>4</sup>

Research amongst workplace leaders with chronic illness suggested that leaders were more likely to conceal their condition if they believed stigma would arise as a result.<sup>4</sup>

Jonathan Smithers, CEO of Arthritis Australia says arthritis has been typecast as an old person's disease. “There is a perception it is always the older person in the workplace complaining about their back pain or knees.”

Samineh Sanatkar, Research Fellow at the Black Dog Institute says people with mental health conditions may avoid disclosure because of stigma and fear of discrimination or prejudice

attitudes they may encounter. However, if a senior leader or employee discloses their medical condition, juniors are more inclined to disclose their own conditions as they see that it won't interrupt their career or career progression.

Carl Cincinnato, Director of Operations, The Brain Foundation says the lack of understanding about chronic migraines contributes to the stigma and discrimination of those impacted. “This is because most people experience a headache that is mild and self-resolving. Migraine, on the other hand, can be severe and debilitating yet individuals who suffer at work are wrongly perceived as “sensitive” or “weak”. Currently, there are very few companies where employees feel it is safe to talk about migraine without fear of judgment or discrimination.”

Taryn Black, Chief of Strategy at Diabetes Australia says one of the main reasons people are contacting her organisation is around workplace discrimination and to understand their rights. “People living with type 1 diabetes have reported experiencing pronounced stigma in the workplace due to the need to inject themselves with insulin and the stigma that still exists due to being mistaken for illicit drug use. People living with type 2 diabetes experience stigma associated with misconceptions that the condition is only brought on by lifestyle factors.”

“There is a perception it is always the older person in the workplace complaining about their back pain or knees.”

**Jonathan Smithers,**  
CEO of Arthritis Australia

“I have had diagnosed mental health issues for 15 years. I have never disclosed this to an employer. Even now, in 2024 when society is much more accepting, I still believe that disclosing mental health issues would put me straight on the ‘do not promote’ list.”

Anonymous research participant. Male, aged 40, office based manager, SA, living with mental health condition



# Career planning and progression

Chronic conditions can impact career opportunities taken or not pursued. It may be that an individual doesn't apply for a job, new role or a promotion because of their condition, leaves a job because of their condition, or feels they are overlooked in terms of opportunities at their current workplace.

*The Chronic Health Conditions in the Workplace 2024* survey found half (52%) of Australian workers with a chronic condition have not applied for a position or job because of their condition.<sup>5</sup>

More than one in three (37%) have left a job because of their chronic health condition.<sup>5</sup> Stress is the greatest contributing factor in the workplace leading to people leaving their job (56%), followed by lack of support for their condition (44%) and difficulty in managing their symptoms at work (43%).<sup>5</sup> Fifteen per cent left their job because they did not want to disclose their condition.<sup>5</sup>

"I didn't want to miss out on the job that was in front of me. I did not want to admit that I couldn't do the things that I was being asked to do, even though I knew I couldn't." Kathryn, volunteer at Australian Patients Association

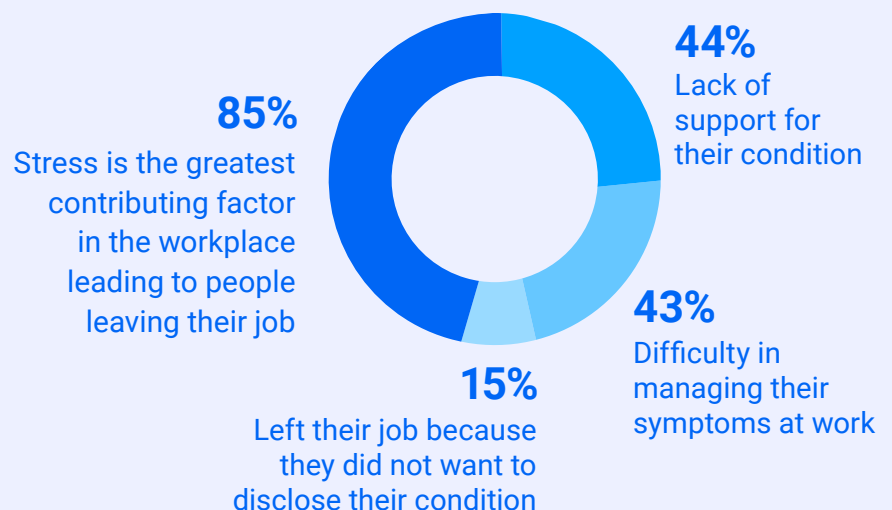
Carl Cincinnato, Director of Operations, Brain Foundation says generally individuals who have chronic migraines and headaches are perceived differently by others around them and by their leaders. They can be seen as a liability and less reliable than others due to the time they may need to take off when they have an acute migraine attack.

“My condition has really shaped where I go and the career moves that I've made because I've tried to gravitate towards the more safe environments rather than, taking strides when I know that I'm capable of so much more than what I'm doing.”

**Rose Mitchell, NSW, living with Crohn's disease, fibromyalgia, hypermobile ehlers-danlos syndrome, adenomyosis & polycystic ovary syndrome**

Research has found that leaders in the Australian workforce are concerned about the impact of disclosure of a chronic condition on their career and work opportunities. Findings included that 42% of leaders agreed or strongly agreed that their colleagues would think they would be incapable of doing their job, 39% were concerned to some extent that disclosing could mean they would be passed over for a promotion, and 38% agreed or strongly agreed that their career progression would be limited.<sup>4</sup>

More than **one in three (37%)** have left a job because of their chronic health condition<sup>5</sup>





## Mathew's story

Mathew (Mat) Boyd-Skinner, aged 36, left his last job due to what he felt was stigma and a lack of empathy in the workplace for people with chronic conditions.

He has had significant health challenges with bowel problems since the age of eight, including around 40 operations, and due to his condition, he has had a permanent ileostomy, where part of the small bowel is brought through the abdominal wall via a surgically-created opening called a stoma, creating an alternative route for bowel movements.

His prior workplace, a fast-food chain where he worked before he had the stoma operation, was not a positive experience. "Their care factor was absolutely zero," Mat says. "I think it's the workplace culture. They didn't want to try and understand what I may be going through. Because the Crohn's disease wasn't visible, they didn't believe I was sick and that's something that I struggled with and why I ended up leaving."

Recovery was difficult after the most recent operation, but he now has a casual job as a barista working with a very understanding team.

"When I applied for this job, I said I can't lift anything over five kilos so I can't lift a milk crate full of milk, and it's never been a problem," he says. His workplace is a mobile café truck

so if there is no nearby toilet that can be an issue if he needs to empty his stoma bag.

Mat is happy to share as much or as little as his co-workers want to know about his condition. His only ask is that people understand that he is living with a chronic condition and ask questions as to how it may impact his day-to-day health.

"When I was being interviewed for the barista job I just said, look I've got Crohn's," Mat says.

"I've got a bag. If you have any questions, ask. The reason why I'm easy about that is because there isn't enough awareness. If they want detail, I'll give them detail. If they don't want detail, I won't."

Mat is adamant he doesn't want sympathy, maintains a bright outlook and pursues his passion occasionally directing theatre. He has even had a tattoo marking the date of his stoma and given it a name, Homer the Stoma - a reference to the Simpsons.

Mat wants to help raise awareness about his condition to help others in their workplaces.

"I still really suffer from fatigue and people are like, oh, it's just fatigue," he says. "But you can literally go to bed, get eight hours of sleep and wake up like you've had none. Unless you suffer from Crohn's disease you don't know what it is."

"I just want people to have more of an understanding of what we go through."

# Making reasonable adjustments

Three in five (61%) workers responding to the *Chronic Health Conditions in the Workplace 2024* survey said they strongly or somewhat agreed their workplace could be making more reasonable conditions of work.<sup>5</sup>

Suggested improvements include flexibility or ensuring people with chronic health conditions don't need a medical certificate every sick day, and physical/environmental adjustments for people, such as making a room available for administering medication, or a fragrance-free zone for people with migraines and headaches.

The adjustments the survey respondents said were most often offered by workplaces are:<sup>5</sup>



**53%**

flexible working hours



**53%**

support to take time for medical appointments or treatments



**38%**

access to an Employee Assistance Program



**37%**

a modified or reduced workload



**Two in three (67%)** believe workplaces should be more inclusive with flexible hours or scheduling and **63% believe more can be done to support individuals** to take time for medical appointments or treatments.<sup>5</sup>



Workers living in capital or large cities are more likely than those in regional or remote areas to have remote work options offered as an adjustment for people living with a chronic condition.<sup>5</sup> Over a third (38%) of those with a chronic condition living in capital or large cities were offered remote work options compared with 26% of those with a chronic condition based in regional or remote areas.<sup>5</sup>

Despite adjustments in workplaces, workers still believe more can be done to further improve inclusivity for people with a chronic condition. Two in three (67%) believe workplaces should be more inclusive with flexible hours or scheduling and 63% believe more can be done to support individuals to take time for medical appointments or treatments.<sup>5</sup>

More than half would also like to see more workplace policies to support individuals (57%), a modified or reduced workload for those with a chronic condition (54%) and the provision of education to all employees on chronic conditions (52%).<sup>5</sup>

A University of Melbourne paper *Disclosing Illness at Work*, recommended that employers maintain flexible/hybrid work settings as a 'default' for all workers who have a chronic health condition that impairs their capacity to work; and that employers embed chronic illness into their existing diversity and inclusion plans and take active steps to consult their chronically ill employees on their needs.<sup>4</sup>

Carl Cincinnato, Director of Operations, The Brain Foundation says people managing a chronic condition should have the ability to recognise workplace triggers, feel comfortable voicing these concerns, and seek understanding and support from those around them.



“A colleague has MS (multiple sclerosis). Her commitment and quality of work is much better than others yet work will not allow her to work from home.”

**Anonymous research participant, female aged 60, office based middle manager, VIC, does not have a chronic health condition**

Taryn Black, Chief of Strategy at Diabetes Australia says, employers need to understand that diabetes is a highly individualised condition and adjustments will vary depending on the type of diabetes, the level of management and how comfortable employees are with their co-workers knowing about their condition. “Another important adjustment is once someone discloses they have diabetes, nominating a person who can help recognise and support them if they are having a hypo at work.”

It is not the case that with time everything becomes easier. The burden of a chronic

condition for an individual can increase years after diagnosis. Samineh Sanatkar, Research Fellow at the Black Dog Institute says it is important to check in with the employee and see how they are faring and for the employer to think about how they can reasonably accommodate for an individual’s current needs. “When employees don’t hear from their employer about these topics they can feel isolated and uncomfortable, especially if they have to take the initiative to ask for further adjustments to be made for them.”

# Creating inclusive workplaces

While diversity and inclusion in the workplace has made significant advances in areas such as LGBTQIA+ rights and gender equality, the needs of individuals living with chronic physical and mental health conditions may be under-represented in workplace discussions.

Yet Australian workers believe those with chronic health conditions deserve fair opportunities at work, with more than four in five (85%) strongly or somewhat agreeing it is important for people with a chronic condition to have opportunities to stay in the workforce, according to *The Chronic Health Conditions in the Workplace 2024* survey.<sup>5</sup> Eight out of 10 (82%) agree remaining in the workforce can help individuals with a chronic condition to have a stronger sense of purpose, to maintain a daily routine and connect with others.<sup>5</sup>

More than two in five workers (45%) know someone living with a chronic condition who has made a significant contribution in their workplace.<sup>5</sup> The stories of these contributions include themes of resilience, advocacy, providing education and being diligent workers.

To ensure people with chronic conditions are able to make contributions at work, Australians felt workplaces could improve the support they provide. More than one in three (38%) felt their workplace did not have an inclusive environment for people with chronic conditions.<sup>5</sup>

They believe that the availability of support and flexibility has the greatest impact on employees with chronic conditions being able to perform

their best at work (37%).<sup>5</sup> This is followed by co-workers being compassionate and empathetic to an individual's unique situation (26%), and employer policies supporting those with a chronic condition (22%).<sup>5</sup>

Taryn Black, Chief of Strategy at Diabetes Australia says, there is a lot for employers to consider with the rise in chronic conditions in Australia if they are aiming to be an employer of choice and have a productive workforce. "It's a pertinent issue for workplaces to think about."

**“In my current workplace I find that when I am open with management about my chronic illness they are more understanding and lenient with me. A past employee fought for extra sick days to be available for employees suffering with chronic illness.”**

**Anonymous research participant.  
Female, aged 30, NSW, office based  
leader living with asthma, back pain,  
mental health and endometriosis**

**More than four in five Australian workers or**



**85%**

strongly or somewhat agree it is important for people with a chronic condition to have opportunities to stay in the workforce.<sup>5</sup>



**More than one in three (38%)** felt their workplace did not have an inclusive environment for people with chronic conditions.<sup>5</sup>

“In my current workplace,  
all employees with a chronic  
condition are supported  
and treated with respect.”

Anonymous research participant.  
Female, aged 66, VIC, works from  
home part time, living with an  
autoimmune disease



# Workplace education

Our patient focus group told us that most people's knowledge of chronic health conditions was limited to their own personal experience or from being exposed to public health awareness campaigns. However, *The Chronic Health Conditions in the Workplace 2024* survey showed there is an appetite amongst Australian workers for education in the workplace about these conditions.

The survey found three in four Australian workers (73%) strongly or somewhat agree that having chronic conditions shouldn't impact how people are perceived, but it often does.<sup>5</sup>

While half (53%) of workers believe people with chronic conditions should be perceived the same as any other employee, this research shows there is still considerable need for education overall.<sup>5</sup>

Half (51%) of workers feel people with chronic conditions can be seen as a burden because they can't complete certain tasks as efficiently as their other co-workers.<sup>5</sup>

Two in three (66%) of workers feel the perception of people with chronic conditions in the workplace is influenced by the personal opinions and level of education of their leaders and peers, emphasising the opportunity for education on chronic conditions in the workplace.<sup>5</sup>

They cite a significant barrier to disclosing having a condition to their employer is a belief that employers are generally not understanding of chronic conditions (33%).<sup>5</sup>

One in three (37%) Australian workers manage an employee with a chronic condition.<sup>5</sup> Of those managing someone with a chronic condition,

three in five (58%) feel extremely or very equipped to do so, while two in five (40%) feel just somewhat or slightly equipped.<sup>5</sup>

"There is a need to increase education and awareness among co-workers that arthritis does not just impact older employees who are over the age of 65 and are at the end of their career." Jonathan Smithers, CEO of Arthritis Australia

Just 22% of Australian workers have received education on chronic conditions in their workplace, however 83% would participate if education on chronic conditions was offered.<sup>5</sup>

Medium sized businesses are leading the charge with 28% of workers in an organisation of 20 to 50 employees having received education on chronic conditions.<sup>5</sup> The percentage of workers being educated in other sized organisations are:

- 15% for those with 5 to 19 employees, 26% for those with 51 to 100 employees, 22% for those with 101 to 199 employees, and 21% for those with 200 or more.<sup>5</sup>

"It is important for employers to properly understand the issues faced by their employees who are living with arthritis in order to make the modifications necessary to help them fulfil their potential," says Jonathan Smithers, CEO Arthritis Australia.

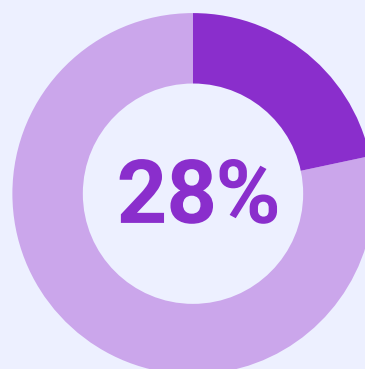
Taryn Black, Chief of Strategy at Diabetes Australia says educating co-workers to have a general understanding of diabetes is critical in creating an inclusive and supportive workplace. Ms Black says employers also need to become educated in the mental health aspect of living with a chronic condition and learn how they can build and teach employees resilience in managing their condition.

**“There's a level of alienation that comes with something that's hidden. Chronic conditions are not easy to see, and therefore not easy to understand.”**

**Sasha Simon, age 31, NSW, living with ankylosing spondylitis**

**Just 22% of Australian workers have received education** on chronic conditions in their workplace, however **83% would participate** if education on chronic conditions was offered.<sup>5</sup>

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**15%**

for those with 5 to 19 employees

**26%**

for those with 51 to 100 employees

**22%**

for those with 101 to 199 employees

**21%**

for those with 200 or more



# Workplace support

Providing support to people with chronic conditions in the workplace is a key area for improvement with managers identified as playing a big role, and having the biggest potential impact on employees experiences.

“It just makes life so much easier when you have such understanding bosses.” Mathew (Mat) Boyd-Skinner, aged 36, NSW, living with Crohn’s disease.

“There was a time when I was facing some severe mental health challenges. My manager was very supportive and did not push for me to share my personal battle. My work made me feel that my health and wellbeing came first and work came second which was amazing.” Anonymous research participant. Female, aged 37, VIC, works from home part time in non-managerial role, living with back pain and a mental health condition.

*The Chronic Health Conditions in the Workplace 2024* survey found a third (32%) of workers with a chronic health condition are most likely to approach their manager for support at work.<sup>5</sup>

In addition, a quarter (25%) turn to their organisation’s confidential Employee Assistance Program (EAP) and one in five (20%) seek support from their Human Resources department.<sup>5</sup> Fifteen per cent seek support from a work colleague.<sup>5</sup>

However, 18% said there was no person or place to go to for support in their workplace.<sup>5</sup>

Of the one in three (37%) workers with a chronic condition who have left a job due to their condition, 44% cited a lack of

support for their condition as a contributor to their decision.<sup>5</sup> Lack of support was the second highest reason for leaving their job, with stress exacerbating their condition being the number one contributor at 56%.<sup>5</sup>

Ten per cent said they had not needed to seek support for their condition in their workplace.<sup>5</sup>

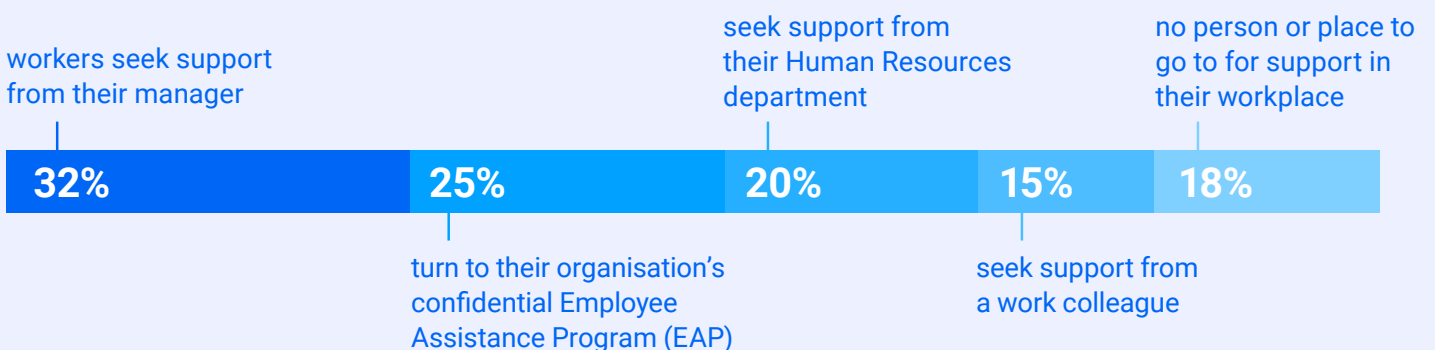
Patient advocacy groups can provide an important supportive role with advice and resources that can be useful for the employee and the employer. For example, Crohn’s & Colitis Australia has an e-book for employers and another for employees on how to manage Crohn’s disease and ulcerative colitis in the workplace.<sup>10</sup>


The Black Dog Institute has seen an increase in workplaces establishing support systems for people with mental health conditions.

Samineh Sanatkar, Research Fellow at the Black Dog Institute says workplace support systems have been shown to help with staff retention and productivity. The Institute’s workplace engagement team runs training programs for employees who would like to detect where they can improve their workplace from a mental health perspective.

“My line manager, living with endometriosis and Crohn’s, helps everyone so often, and I couldn’t imagine I would still be there through my chronic condition without her support.” Anonymous research participant. Female, aged 25, NSW, part time employee, living with postural orthostatic tachycardia syndrome (POTS), asthma, a mental health condition and endometriosis.

## The Chronic Health Conditions in the Workplace 2024 survey found<sup>5</sup>:





“I hope that by sharing my experiences, I can contribute to a broader dialogue about chronic illness in the workplace.”

**Anonymous research participant.**  
Male, aged 30, NSW, executive leader,  
healthcare facility, living with cancer

# Conclusion

This report has highlighted considerable needs and opportunities to better support people living with chronic conditions in the workplace.

Disclosure of a chronic condition is a key dilemma with half of Australians revealing in *The Chronic Health Conditions in the Workplace 2024* survey that regardless of whether living with a chronic condition or not, they would not be likely to disclose this to their employer. Whilst naturally some will want to treat their health as a personal matter, others raised fear of discrimination or impact on their career progression and opportunities for advancement as reasons not to disclose their chronic health condition.

Without being confident enough to disclose their condition, individuals may be limiting the potential for their manager or employer to provide support and offer relevant workplace adjustments that may enable them to fulfil their potential in their role.

Education of employers and co-workers has been identified as being an area of great need and one that in turn will offer great value both practically and culturally to individuals and the workplace. There is also a readiness for education and desire for better understanding of chronic health conditions amongst co-workers so they can support their colleagues.

The findings from this research have provided a launchpad for an important conversation that needs to happen in workplaces across Australia.

This report has only scratched the surface of some of the issues. There is a need to engage more widely with employers, people living with chronic health conditions, chronic disease organisations who advocate on their behalf and policy makers.

AbbVie will be using the findings of this report to bring together stakeholders to identify how we all can better support individuals with chronic health conditions in the workplace.

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