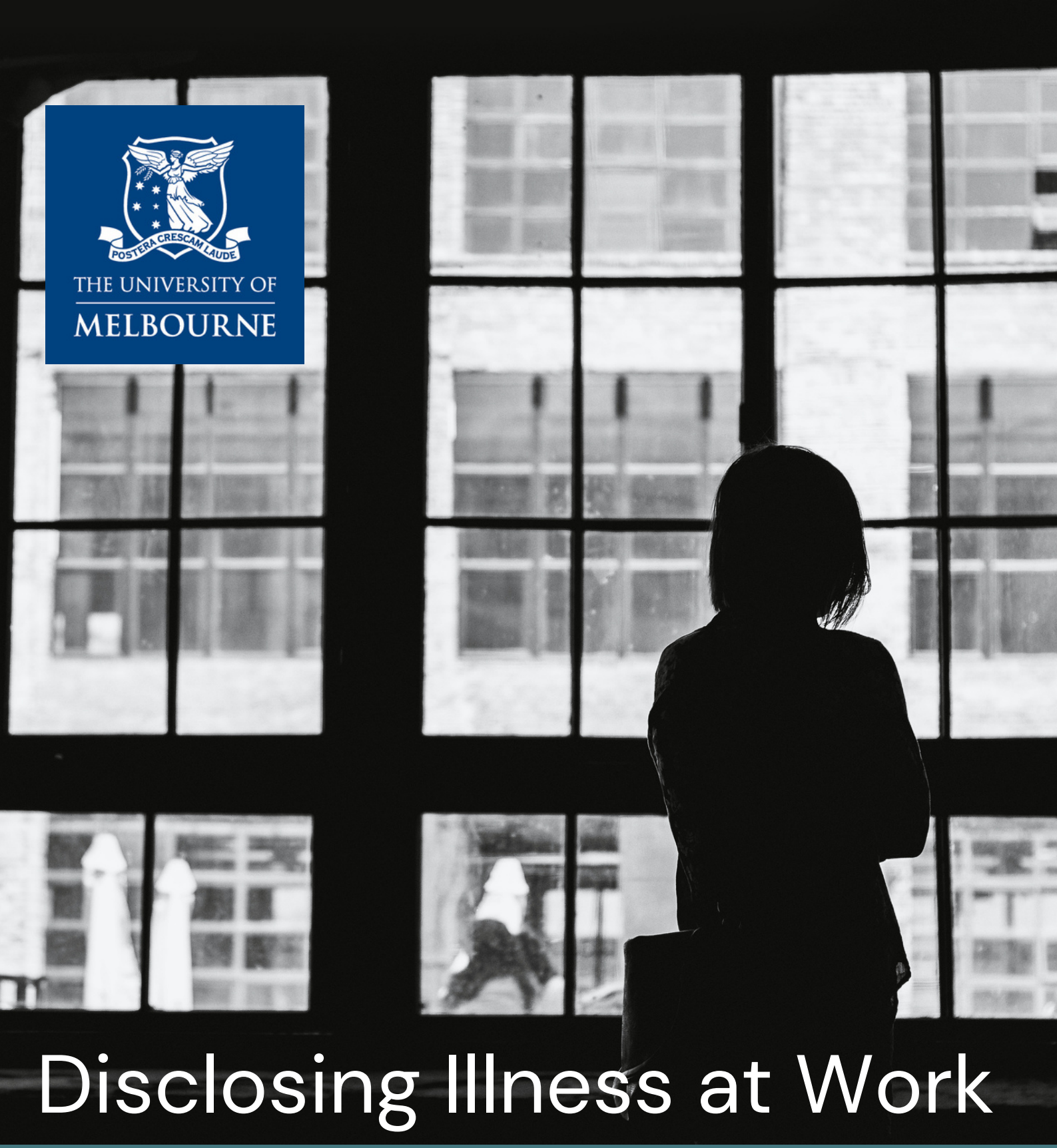


THE UNIVERSITY OF MELBOURNE

Disclosing Illness at Work

A survey of leaders living and working with chronic illness

MAY 2023

Authors

Dr Peter Ghin, Research Fellow, University of Mellbourne
Dr Mladen Adamovic, Senior Lecturer, Kings College London
Prof. Susan Ainsworth, Professor of Organisation Studies, University of Melbourne

Acknowledgements

Thank you to Dr Max Theilacker for his early stewardship of this project. This research was partly funded by a grant from the Faculty of Business and Economics, the University of Melbourne.

Citation

Ghin, P., Adamovic, M., & Ainsworth, S. (2023). Disclosing Illness in the Workplace: A survey of leaders living and working with chronic illness, The University of Melbourne, Melbourne, Vic.

ISBN

TBC

For further information about this report please contact
peter.ghin@unimelb.edu.au

Table of Contents

Introduction

The coronavirus pandemic has brought to the fore the plight of a previously ignored group of workers – people living with a chronic illness.

The indiscriminate and enduring effects of long-COVID and the impact of the pandemic on workers' mental health, have highlighted the challenges that people living with long-term health conditions face participating in workforce.

The most recent Census found that 8 million Australians, or 32 percent of the population, were managing at least one long-term health condition[i]. Recent research suggests that 38 percent of working age Australians identify as living with a chronic illness. Three quarters of chronically ill workers indicate that their condition affects their capacity to work[ii].

An employee managing a long-term health condition will invariably find themselves weighing up the decision to disclose their illness with their employer.

Disclosing an illness can enable workers to request reasonable adjustments to better accommodate their changing circumstances. It can also encourage employees' feelings of agency and organisational support as they take steps to assert control in a time of increased vulnerability and uncertainty.

Some workers may be reluctant to disclose their health condition to their employer because they anticipate they will be treated less favourably than someone without a chronic illness. Research has found that people living with chronic illness experience a higher incidence of discrimination than any other category of employee[iii].

Both Commonwealth and State laws in Australia (e.g., Disability Discrimination Act, 1992; Fair Work Act, 2009); make discriminating against, harassing or victimising people with disabilities unlawful. Some States in Australia impose a positive obligation on employers to make sure their workers do not experience disability discrimination because of their employment (e.g., Disability Act Victoria, 2006). Workers also have the right to make a complaint to external agencies, such as the relevant Human Rights and Equal Opportunity Commission.

Despite these protections, many employees will be reluctant to disclose their chronic illness status in the workplace. Partly this is because of the nature of chronic illness itself. Unlike an acute illness, a chronic illness is a long-term health condition that requires

ongoing management, may involve episodic flares, and is likely to be associated with comorbidities that make the condition more complex to manage.

These factors mean that a chronic illness becomes more enmeshed with an individual worker's identity, often making an ongoing impairment more challenging to negotiate in the workplace.

Disclosing Illness as a Leader

This report seeks to better understand the illness disclosure behaviours of people in leadership positions. According to our analysis of the latest Census data, managers and professionals make up 38 percent of the workforce who have been diagnosed with a chronic condition by a medical professional - over 1 million Australian workers [iv].

The sheer volume of skilled workers this represents speaks directly to the policy challenge that lies before employers and governments to prevent people with long-term health conditions from leaving the workforce and becoming part of an invisible talent pool [v].

The reluctance to disclose a chronic illness at work can be magnified for those individuals who occupy positions of leadership, in part because of the increased organisational visibility and accountability that is associated with higher status roles.

There are also pervasive social stigmas associated with chronic illness, particularly mental illness, which may instill fears about how a leader's competency, career progression, and reputation may be affected by an illness disclosure.

Furthermore, the concept of leadership is itself deeply embedded in what are believed to be traditionally masculine traits such as strength, invulnerability, vitality, and decisiveness[v]. Therefore, when a leader is faced with coming to terms with an ongoing impairment, their very identity as a leader can be confronted.

This is perhaps even more true for those leaders who already exist at the margins of a traditionally ascribed leader identity and carry the weight of minority representation (e.g., women, non-conforming genders and sexualities, people of colour etc.).

By focusing on people in positions of leadership, the findings of this report reinforce that managing long-term illness is part of the lived experience of many workers, regardless of their position within an organisational hierarchy.

This report also contributes to an important discussion about the need for organisations and governments to respond proactively to the needs of this growing cohort of workers or face losing them and their significant skills from the workforce.

Key Findings

1 Disclosure of chronic illness was mostly partial, full disclosure was more common when leaders felt psychologically safe and supported by their organisation

Our research found that leaders were more likely to partially disclose their illness (**54 percent**), with just over a quarter of leaders revealing little or nothing about their chronic illness to their employer (**28 percent**), and only **18 percent** of leaders fully disclosing their illness in the workplace. Leaders were also more inclined to fully disclose their illness the more visible and severe it was, and when they felt psychologically safe and supported by their organisation.

2 Leaders were more likely to disclose illness to their supervisors but were reluctant to communicate the extent of their impairment

On average, leaders indicated they more inclined to fully disclose their illness to their supervisors (**24 percent**) than with HR representatives (**16 percent**), or their peers and/or subordinates (**15 percent**). However, leaders were very selective about the information they revealed. They were more likely to disclose general information about their illness rather than be transparent about the extent to which their work was impacted by an impairment.

3 A majority of leaders engaged in behaviours to actively conceal or minimise the visibility of their illness

We found that over two thirds of leaders (**67 percent**) reported that they were actively managing their appearance to some extent in order to minimise the visibility of their illness. **77 percent** of respondents reported that they downplayed the importance of their illness in the workplace and almost three quarters of leaders (**73 percent**) acknowledged that they tried to hide their symptoms when in the workplace. We also found that the higher a leader's anticipation of stigma in the workplace, the more likely they were to conceal their health condition.

4 Leaders were concerned that disclosing their chronic illness would have negative career impacts

Leaders had concerns that disclosing an illness would effect peoples' perceptions of their competency, and, in turn, impact their career trajectory. **42 percent** of respondents either agreed or strongly agreed with the statement, *my colleagues would think that I was incapable of doing my job,* and **39 percent** were concerned that disclosing an illness would mean that they would be *passed over for promotion*. Leaders with severe illness were more concerned about the impact of a disclosure on their perceived competency and career.

5 Most leaders had no regrets about disclosing their illness

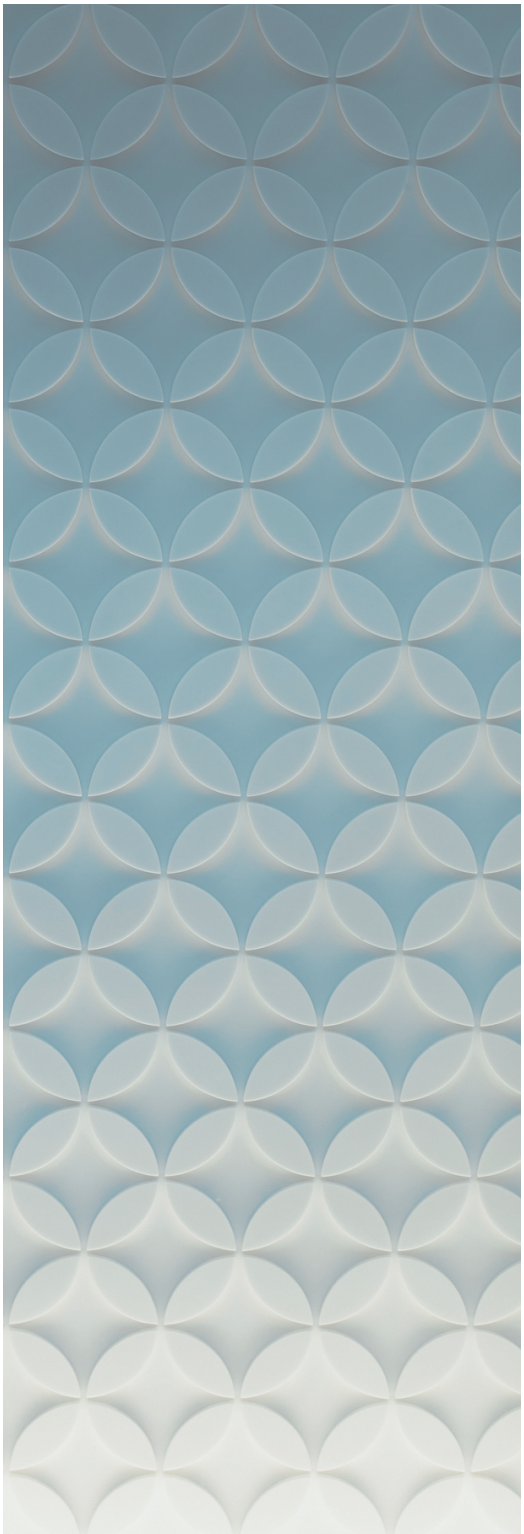
69 percent of leaders indicated that they had no regrets about disclosing their illness, with **75 percent** of respondents likely to do so again. Although these findings suggest that the disclosure experience had been a positive one for most leaders, there were some caveats. For instance, leaders with less severe and less visible chronic illnesses expressed significantly fewer regrets about disclosing their long-term health conditions that those with more severe illnesses. Also, people with a mental illness were far less emphatic about the positive impact of disclosure for them than those who had a physical illness.

6 A majority of leaders had requested some form of reasonable adjustment from their employer

We asked respondents whether they had requested any reasonable adjustments from their employer and found that **73 percent** of leaders requested some form of workplace accommodation from their employer, with the majority of these (**61 percent**) being minor in nature (e.g., the purchase of an ergonomic chair). Only **12 percent** of leaders requested a significant workplace adjustment, such as a major modification to a work schedule. Leaders with a very severe chronic illness were more than twice as likely to have requested significant workplace adjustments than those who had a moderately or severe illness (**68 percent vs. 32 percent**).

Policy Recommendations

While the focus of this report is on the disclosure behaviours of chronically ill leaders, the findings have policy ramifications that extend to all Australian workers who are managing a long-term health condition. This research was conducted in a pre-pandemic era, when there was a dearth of policy focus on issues pertaining to chronic illness and employment. The COVID-19 pandemic has altered this landscape.



There is now a growing awareness of the individual and societal impacts associated with the diminished working capacities of people living with a chronic illness. In Australia, it has been estimated that the reduction in peoples' working capacity due to the effects of long-COVID is costing the national economy $100 million per week and up to $5 billion per year[vii].

The economic impacts of chronic illness more broadly are estimated to cost the Australian economy $27 billion, however, this does not include costs associated reduced employment participation; in particular, the economic burden caused by workplace absenteeism and presenteeism due to compromised health[viii].

Despite these costs, however, there has been a fundamental inability to reckon with the structural changes that may improve the accommodation of chronically ill workers and ensure that these individuals do not exit the labour market.

The pandemic saw some significant gains for people living with a chronic illness, namely, the increased availability of remote working and the ability for people to work from home. For people with limited mobility, energy limiting conditions, and other restrictive chronic health conditions, this degree of flexibility was a game-changer. As organisations reconsider their post-pandemic workforce planning, there are fears that these modest gains will be erased as some employers may insist on a return to onsite work as the norm.

Recommendation 1
Employers must maintain flexible/hybrid working settings as a default for all workers who manage a chronic health condition that impairs their capacity to work.

While employers have continued to hone and implement their diversity and inclusion strategies, these rarely include any provision for people who are living with a chronic illness. This is a considerable oversight given the sizeable proportion of workers that are managing at least one chronic health condition.

Recommendation 2
Employers must embed chronic illness into their existing diversity and inclusion plans and take active steps to consult their chronically ill workforce on their needs.

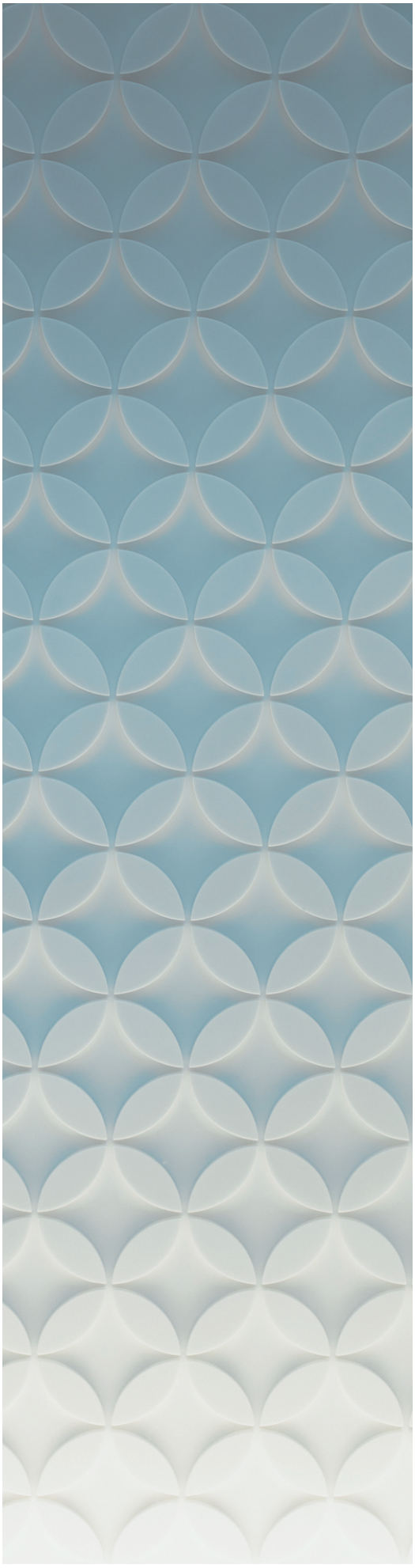
While chronically ill employees have the right to request workplace adjustments once they are employed, there are currently few steps being taken to design jobs that will attract workers who are managing a long-term health condition. Consequently, there is an invisible talent pool that is excluded from applying for jobs because the default job design for secure work lacks the flexibility and autonomy required for many skilled workers living with a chronic illness.

Recommendation 3
Encourage employers to think innovatively about job design during the recruitment phase so that they can attract skilled workers living with a chronic illness into the workforce.

In a post-pandemic era of skills shortages and labour hire restrictions, more attention needs to be given to better understanding how to improve the recruitment and retention of chronically ill employees in the workforce.

Recommendation 4
Governments should invest in supporting recruitment programs that specifically focus on engaging chronically ill populations who have a desire to re-enter the workforce, and commission high-quality research into the barriers and enablers of engaging this cohort of workers.

As this research has shown, managers are usually the first point of contact for employee disclosure of a long-term health condition. Therefore, a manager's response is critical to ensuring that the needs of chronically ill workers are validated and supported by the organisation from the outset. These can be challenging conversations for all parties, so it is important that managers are also supported to effectively navigate the relational and bureaucratic challenges of illness disclosure in the workplace.



Recommendation 5
Organisations should ensure that managers have access to appropriate training to effectively manage the disclosure of long-term health conditions, and ensure chronically ill workers are supported to remain in the workforce.

Employers vary in their capacity to dedicate resources to respond to the needs of workers with chronic illness. Some are large and have dedicated diversity and inclusion functions, while others are small and may have more limited access to resources. All employers should be able to reap the benefits of making employment more accessible and support should be available for them engage more deeply with chronic illness inclusion practices.

Recommendation 6
Governments should fund the research and development of a best practice toolkit to support all employers wishing to recruit and retain employees living with a chronic illness. This toolkit should be publicly available, be based on the latest evidence, and cater to employers of all sizes.

Although this report has focussed on leader behaviours, our findings have implications for workers and organisations more broadly because leaders can be role models for illness disclosure. Normalising the visibility of long-term health conditions will likely have a significant (positive) effect on the psychological safety of chronically ill workers and create an inclusive workplace culture.

R**ecommendation 7**
Leaders should champion an inclusive culture of belonging by becoming advocates for people living with long-term health conditions, using their status to publicly recognise and value the contribution made by their chronically ill workforce.

Key Finding #1

Disclosure of chronic illness was mostly partial, full disclosure was more common when leaders felt psychologically safe and supported by their organisation

Extent of Disclosure

We asked leaders to answer a series of questions related to their illness disclosure behaviours in the workplace. Because illness disclosure is often a complex, partial, and ongoing process, leaders' responses have been assigned the following categories: full disclosure, partial disclosure, negligible disclosure.

Full disclosure refers to cases where leaders were highly transparent about their chronic illness to their employer, while *partial disclosure* suggests that leaders were more circumspect about the depth of information they revealed. *Negligible disclosure* signifies that people were highly reticent to reveal any details about their long-term health condition in the workplace.

Overall, the survey found that over half of all leaders, **54 percent**, partially disclosed their illness in the workplace. This suggests there was a tendency for most leaders to be cautious about their approach to illness disclosure at work.

Over a quarter of leaders, **28 percent**, engaged in negligible disclosure behaviours, meaning that they told people in their organisation nothing or very little about their long-term health condition. Finally, **18 percent** of leaders indicated they had been fully transparent about their illness with their employer.

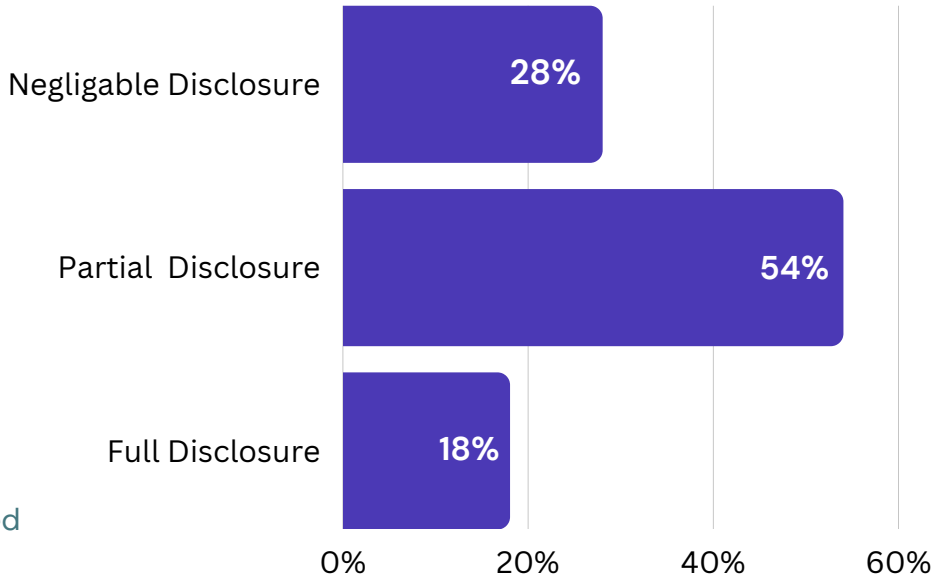


Figure 1: Extent leaders disclosed their illness in the workplace

Full disclosure of chronic illness was positively associated with illness severity and illness visibility. This suggests that leaders who regarded their chronic illness as more severe and highly visible were more likely to fully disclose their illness, while respondents who rated their condition as not severe and not visible were the most likely to engage in negligible disclosure behaviours.

67 percent of leaders who fully disclosed their illness indicated that they were very likely to disclose their illness to an employer in future. By contrast, only **32 percent** of leaders who partially disclosed their illness said they would be very likely to do so again. This finding suggests that those leaders who were more transparent about their illness experienced higher levels of satisfaction with their organisation's response to the disclosure.

However, as discussed below, our research also found that higher levels of disclosure transparency are significantly tied to a leaders' perception of their organisation's culture. Therefore, it is not necessarily that greater transparency leads to better outcomes for leaders, but that leaders who fully disclose are more likely to perceive their organisation as a receptive environment to enable that disclosure to take place.

Impact of organisational culture on disclosure behaviours

In order to feel comfortable sharing information about their long-term illness, leaders must feel that there is an organisational climate within which it is safe to make such a disclosure.

Our research found that there was a correlation between feelings of psychological safety and full disclosure, that is, the more a leader trusted their organisation and their supervisor, the more likely they were to fully disclose their illness. Similarly, our research also found that there was a correlation between feelings of organisational support and full disclosure. That is, the more a leader believed that the organisation cared about employees and their well-being, the more likely they were to fully disclose their illness.

Leaders were more likely to *fully disclose* their chronic illness when they felt psychologically safe and supported by their organisation

Taken together, these findings reaffirm the significance of organisational culture in providing an environment that encourages leaders to be transparent about their illnesses. Highly competitive, cut-throat cultures are likely to be experienced as unsafe environments to disclose a condition which reveals an individual leader's vulnerability. By contrast, organisations that accept the ubiquity of chronic illness amongst its senior workforce and have visible policies in place to implement health accommodations for employees, are far more likely to project a supportive culture that engenders greater transparency from its workforce.

Key Finding #2

Leaders were more likely to disclose illness to their supervisors but were reluctant to communicate the extent of their impairment

Who leaders are disclosing to

Survey respondents were asked to indicate who they were disclosing their illness to within their organisation. They were given the following three options: a HR representative, their supervisor, or their peers/subordinates.

Leaders were significantly more likely to be *fully transparent* about their illness with their supervisors than with HR representatives, or their peers/subordinates. **24 percent** of leaders indicated that they fully disclosed their long-term health condition to their supervisors, as compared to only **16 percent** to HR, and **15 percent** to their peers/subordinates.

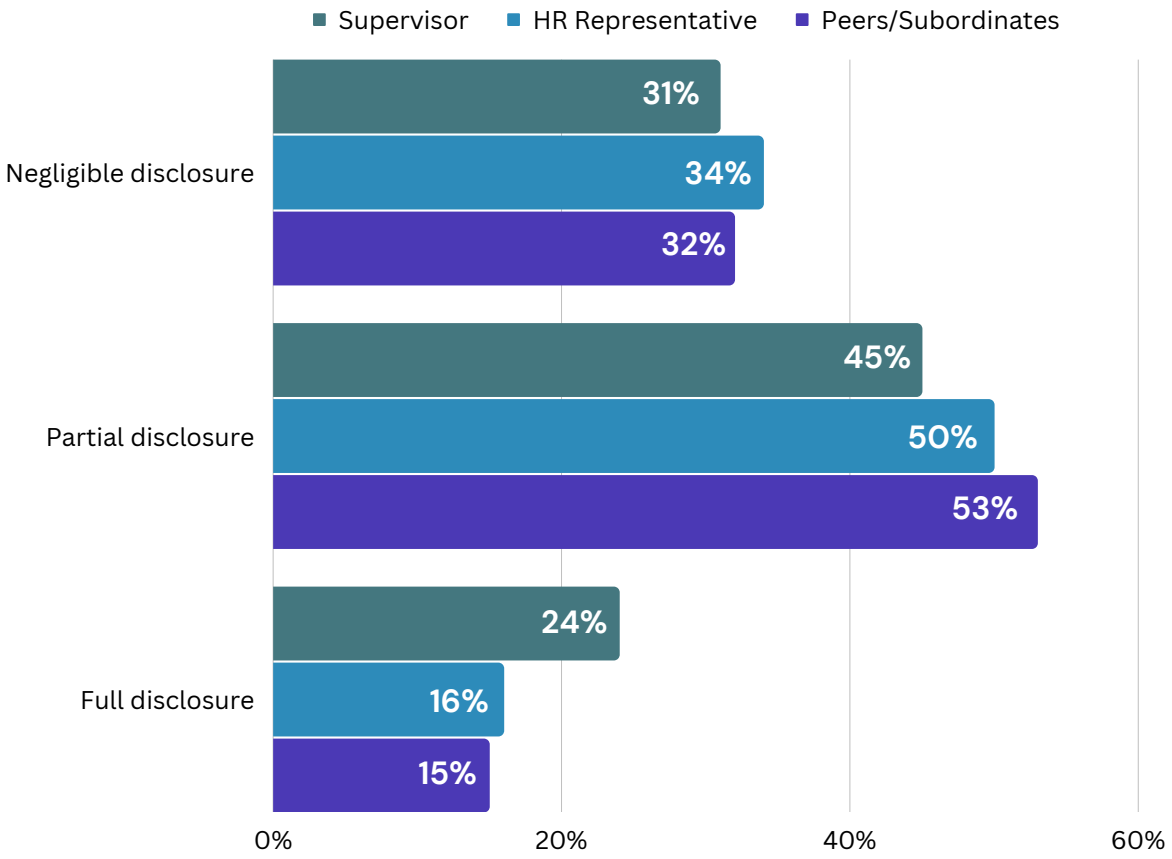


Figure 2: Who leaders disclosed to and the extent of that disclosure

Higher rates of overall disclosure to supervisors are to be expected because these are the individuals with whom any workplace absences and ongoing accommodations will first need to be negotiated.

Unsurprisingly, the survey found a correlation between the levels of trust in the supervisory relationship and an increase in disclosure behaviour. Therefore, the more a leader trusted their supervisor or perceived their supervisor as fair, the higher the likelihood of their disclosure to them.

Our research confirmed that leaders were significantly more likely to partially disclose their illness to their peers and/or subordinates, **53 percent,** when compared to their direct supervisors, **45 percent.** For leaders, the process of disclosing an illness to their direct reports can be particularly challenging. This is especially true when leading large teams or where an illness is likely to result in periods of absence, which can create a period of organisational uncertainty.

Nature of information diclosed

Survey respondents were asked a number of questions to determine what type of information they were disclosing about their long-term health condition. The content of the disclosures was grouped into four categories: i) the type of illness they had and its symptoms, ii) the strategies they had in place to manage these symptoms, iii) their need to take leave to manage their illness, and iv) the extent their illness was impacting their work.

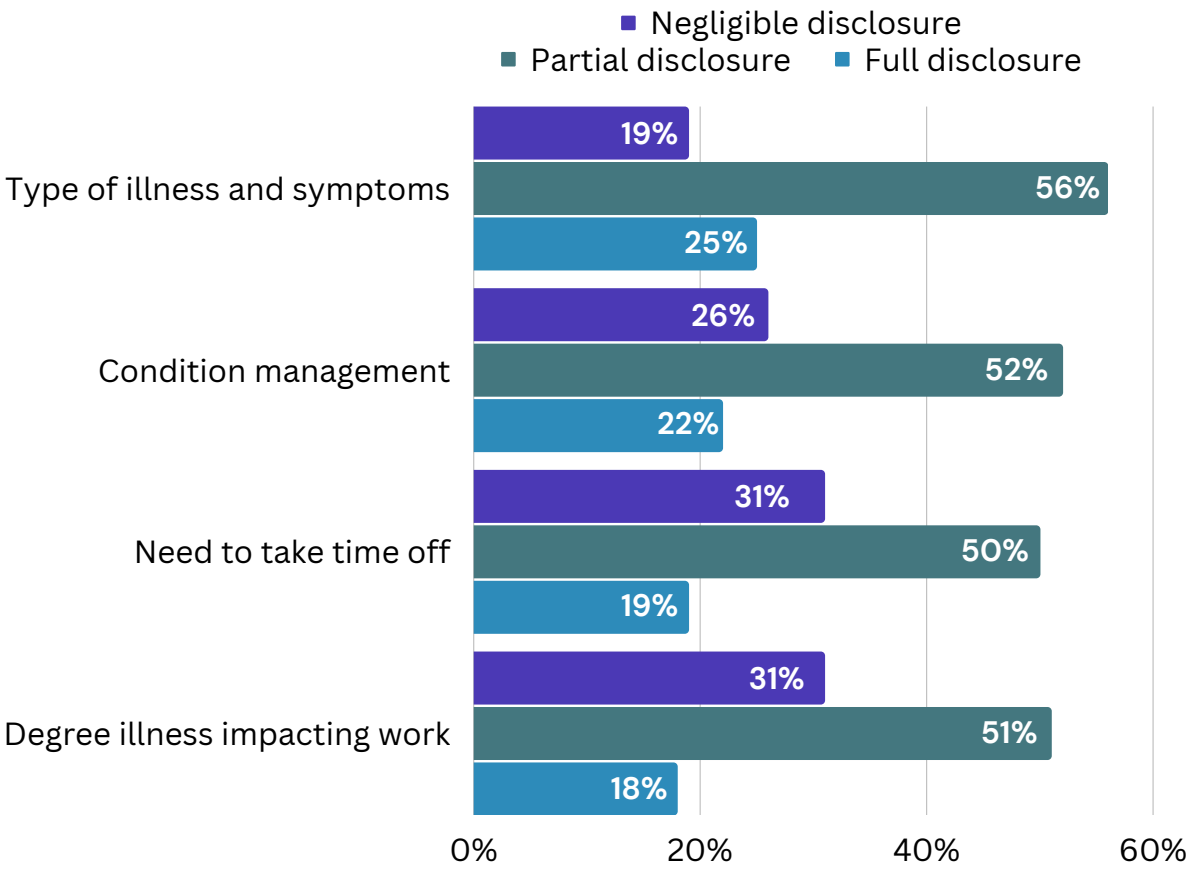


Figure 3: Type of information being disclosed and the extent of disclosure

Our research found that, on average, managers were more commonly transparent about the type of illness they had and its symptoms (**81 percent**), and how they were managing their condition at work (**74 percent**). They were generally less transparent about their need to take time off of work due to illness and the degree their illness was impacting their work (**69 percent** for both).

Looking more closely at the findings for full disclosure, a quarter of managers indicated that they were fully transparent about the type of illness they had, and **22 percent** reported high levels of transparency for how they were managing their condition.

However, full disclosure declined to only 18 percent when it came to being open about the degree an illness was impacting them at work, and 19 percent with regards to their need to take time off due to illness.

It is perhaps not surprising that leaders would be less inclined to fully reveal information that highlights the extent to which their illness is impacting their daily working lives. The stigma associated with many illnesses and the inherent ablest assumptions of leadership, means that such disclosures can invite questions about competence and present perceived risks to career progression (see Finding 4).

"I am very wary of disclosing issues at work as I don't trust my employer not to hold that information against me."

- research participant

Key Finding #3

A majority of leaders engaged in behaviours to actively conceal or minimise the visibility of their illness

Respondents were asked a number of questions about how they managed the visibility of their chronic illness in the workplace. The survey findings suggest that it was not uncommon for respondents to employ management strategies to conceal the extent of their illness while in the workplace. We found that leaders were actively adjusting their appearance, downplaying the seriousness of their illness, or attempting to hide their symptoms whilst working.

Actively managing appearance

Over two thirds of leaders (**67 percent**) reported that they were actively managing their appearance at times so other people in the workplace would not notice their chronic illness. This might mean doing a variety of things such as wearing more makeup, dressing in a way that disguises any visible symptoms, or turning a camera off when in an online meeting.

Downplaying illness

We found that **77 percent** of leaders reported that they downplayed the importance of their illness in the workplace often or sometimes. Only **23 percent** indicated that they never minimised their illness when at work. Downplaying the significance of a chronic illness might include finding ways to explain-away visible symptoms (e.g., a persistent cough), or deftly changing the conversation if someone asks you how you are.

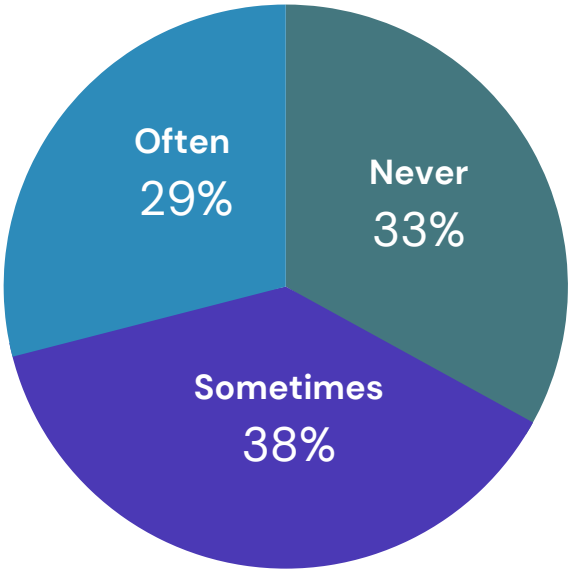


Figure 4: Frequency leaders actively managed their appearance at work

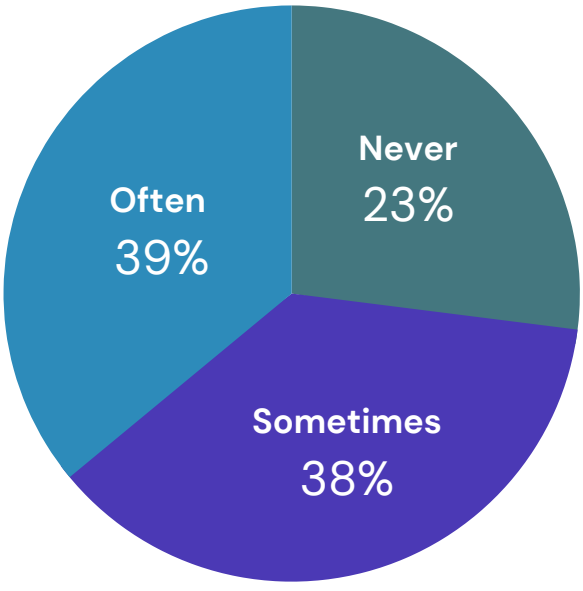


Figure 5: Frequency leaders downplayed the importance of their illness

Deliberately hiding symptoms

Finally, we also asked leaders whether they ever deliberately hid the symptoms of their chronic illness while at work. Hiding symptoms could refer to actions such as not being transparent about the reason for a workplace absence or masking visible symptoms during a meeting. Almost three quarters of respondents, **73 percent**, acknowledged that they often or sometimes tried to hide their symptoms when in the workplace. Less than a quarter, **27 percent**, of respondents indicated that they never did so.

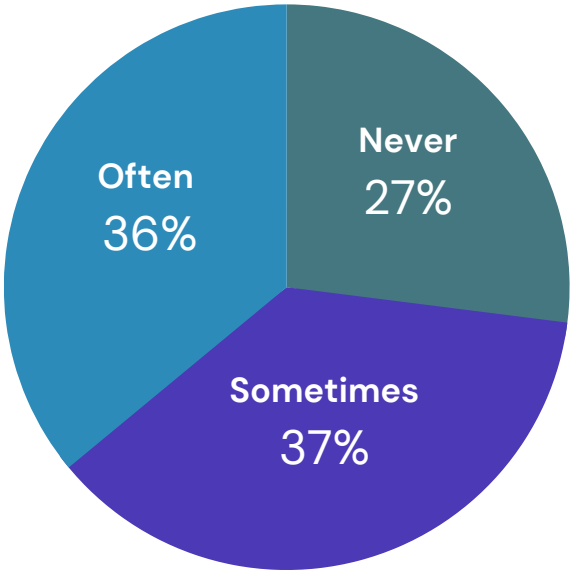


Figure 6: Frequency leaders hid their illness in the workplace

Further analysis suggests that leaders' concealing behaviours are significantly correlated to the anticipated stigma associated with disclosing an illness in the workplace. This means that leaders are more likely to hide their illness at work if they believe that their colleagues would view such a disclosure negatively and/or it would jeopardise their career in some way.

Additionally, perceptions of organisational support seems to be another important factor that influences the extent to which leaders might hide their illness in the workplace. Our research indicates that illness concealing behaviour is negatively associated with organisational support. This means that leaders are more likely to hide their illness if they perceive their organisation as being uncaring towards its employees.

> The higher a leader's anticipation of stigma in the workplace, the more likely they were to conceal their health condition

Concealing behaviours were also correlated to a leader's tendency to seek help for an illness more generally. For instance, if a leader was the kind of person who would be reluctant to seek medical help for a problem normally, they were also more likely to conceal their illness at work.

It is s important to acknowledge that a degree of illness concealing behaviour is to be expected in the workplace. It is a reflex response for human beings to seek to hide their vulnerabilities from others, and many people will not always be conscious they are doing it.

Whilst some chronic illnesses may be visually apparent to others, many are not. For example, someone living with an energy limiting condition, such as long-COVID, chronic fatigue syndrome or an autoimmune disorder, may present as unimpaired to their colleagues. However, they will often be dealing with complex, episodic symptoms that are largely rendered invisible in an organisational context.

People living with a long-term health condition will engage in concealing behaviours for a variety of reasons. Managing a chronic illness often requires a continuous reconstruction of worker and leader identity as people come to terms with their physical and mental limitations, and what this means for their capacity to work.

In choosing to conceal their illness in the workplace, leaders may be: exercising their right to privacy and dignity, seeking to avoid challenging conversations with their colleagues, fearful that they won't be believed, or absolving themselves temporarily from the mental load associated with maintaining a chronic illness identity in the workplace.

However, concealing an illness can become problematic when it is motivated by an individual's denial of their health condition, or if it is the direct response to working in a culture that lacks organisational care. In these cases, a leader's illness concealment can pose a risk to both an individual leader, their team, and the wider organisation.

"I have PTSD and it is something that isn't really accepted or understood as a real condition. I tend to hide a lot of what I'm feeling."

- research participant

Key Finding #4

Leaders were concerned that disclosing their chronic illness would have negative career impacts

Concerns Prior to Disclosing

Prior to disclosing an illness, leaders will be weighing the benefits against the potential costs of that disclosure. We asked leaders to respond to a number of statements that reflected common concerns that employees may have about revealing their illness in an organisational setting.

Our findings reveal that many leaders did not necessarily hold significant concerns about how their colleagues would respond to the disclosure of their chronic illness. For instance, a majority of respondents disagreed or strongly disagreed with concerns such as: *my colleagues would see me as weak* (**53 percent**), *my colleagues would think I was faking my illness* (**57 percent**), *my job commitment would be questioned* (**57 percent**), and *my colleagues would feel uncomfortable around me* (**54 percent**).

These findings may partly be explained by the over-representation of individuals in the sample who self-identified as having a physical illness only (70 percent). Long-term conditions with a mental illness component have a much lower stigma threshold, which means that people in general have more concerns about revealing their mental illness at work.

Our findings suggest that leaders who experienced mental illness were **47 percent** more likely to have general concerns about illness disclosure prior to disclosing their condition at work.

"I was not able to trust those with whom I disclosed my illness to; this may significantly affect my career/work opportunities and growth."

-research participant

Our survey also showed that leaders held deeper concerns regarding perceptions of competency, and the impact that illness disclosure would have on their career trajectory. For instance, **42 percent** of respondents either agreed or strongly agreed with the statement, *my colleagues would think that I was incapable of doing my job*. **39 percent** were concerned to some extent that disclosing an illness would mean that they would be passed over for promotion, and **38 percent** of leaders agreed or strongly agreed with the statement that, *my career progression would be limited*.

42%

"my colleagues would think that I was incapabable of doing my job"

39%

"I would be passed over for promotion"

38%

"my career progression would be limited"

Concerns about the career impact of chronic illness were particularly salient for leaders with severe illness. Leaders' who considered their illness to be very severe were significantly more likely to strongly agree with the statements, *I would be passed over for promotion,* and, *my career progression would be limited,* than those with more moderate impairments.

The survey's findings are consistent with previous research which has found that leaders often hold fears that illness may be equated with incompetence and, therefore, have a significant impact on their career runway[viii].

Traditionally, the ability to exercise mastery over one's body and mind has often been associated with the gendered markers of leadership identity, that is, an effective leader is a fit and healthy one who is in full control of their body and mind at all times.

People in positions of leadership who do not meet this criteria may be less likely to be fully transparent about their chronic illness because of the fear that it undermines their very identity as a leader. Similarly, leaders who do disclose a long-term health condition, may hold themselves to a higher performance standard than their 'healthy' colleagues, to prove that their illness is not an impediment to their competence and career progression.

Key Finding #5

Most leaders had no regrets about disclosing their illness

As with many types of disclosure, becoming more open about one's circumstances can have a liberating effect and help individuals feel seen and cared for, when the response is affirming. For leaders, this can also ameliorate the need to hide symptoms and support actively seeking workplace adjustments, where they may be necessary.

We asked managers if they had any regrets about disclosing their chronic illness in the workplace. The majority of respondents, **69 percent,** indicated that they had no regrets about their illness disclosure, which suggests that the experience of organisational disclosure had been a positive one for most leaders. However, it should be noted that most respondents' disclosures were only partial, that is, they did not generally disclose the full extent of their impairment. Those leaders who did fully disclose their illness, were more likely to state that they often regretted their decision.

"I should have talked to someone sooner."
Research participant

Similarly, our research also found that leaders with less severe chronic illnesses had fewer regrets about disclosing their chronic health conditions. Of those who

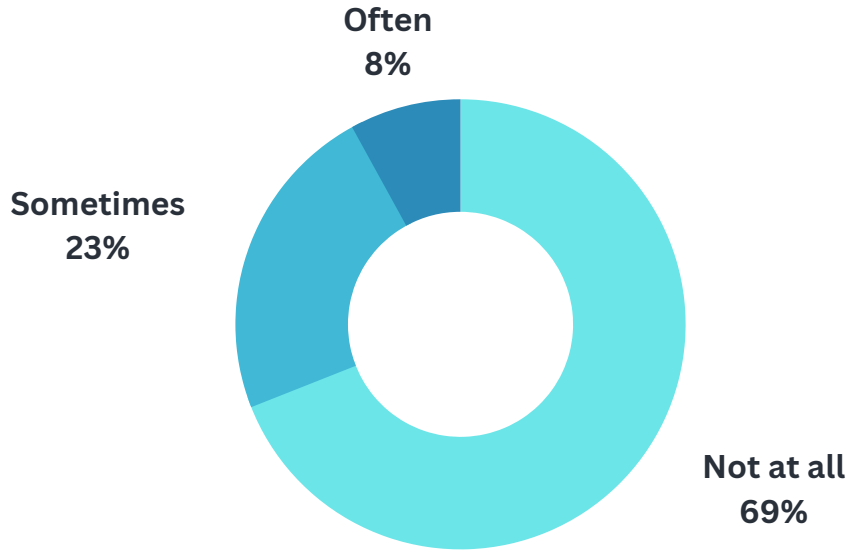


Figure 7: Do you have any regrets about disclosing your chronic illness?

said that they *often* had regrets, **50 percent** indicated that their illness was very severe – people with very severe illness only represented 22 percent of the overall sample. This finding speaks to the challenges of disclosure for leaders whose chronic illnesses are more complex and likely to require ongoing accommodation in the workplace.

Whilst leaders with a mental health condition were not significantly more likely to regret their decision to disclose, they were less emphatic about the positive impact of disclosure. For instance, of those that had no regrets at all about disclosing, **79 percent** had a physical illness as opposed to only **21 percent** who experienced a mental health condition. This suggests some degree of ambivalence amongst leaders about the relative benefits of disclosing a mental health condition in the workplace.

We also asked people how likely they were to disclose their illness again at work, based on their past experience. Given the high percentage of people that had no regrets about disclosing, it was unsurprising to find that **three quarters** of leaders reported that they were likely or very likely to disclose their condition again in the workplace. Only **5 percent** of leaders indicated that they would never disclose their chronic illness again.

85 percent of leaders who indicated that they were very likely to disclose their illness again had a physical illness only, which suggests that people with a mental illness were more equivocal about disclosing illness at work in the future.

Whether a manager chooses to disclose their chronic illness or not, what remains salient is that there is no actual conflict between living with a long-term health condition and being an organisational leader.[x]

Key Finding #6

A majority of leaders had requested some form of *reasonable adjustment* from their employer

The term 'reasonable adjustment' refers to an employee's right to request accommodations from their employer to assist in the management of a disability or chronic condition while at work. Most commonly, reasonable adjustments might include the purchase of equipment, a revised work schedule, and leave arrangements to manage fluctuating symptoms.

People in leadership positions may sometimes be reluctant to request reasonable adjustments because of a perceived stigma of what a request might infer about their ongoing capability to perform their role. There may also be limited flexibility available for people in leadership positions, with fewer people available to cover their workload during periods of absence or incapacity.

Our survey data suggests that **73 percent** of chronically ill leaders requested some form of reasonable adjustment from their employer. The majority of these, **61 percent**, were minor in nature and likely to reflect things such as equipment purchases or changes to working patterns. Only **12 percent** of leaders requested a significant workplace adjustment, such as modifying a work schedule.

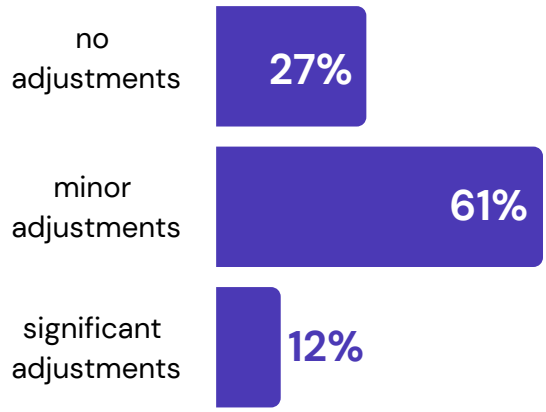


Figure 8: Extent of reasonable adjustment requested by leaders

Leaders who rated their chronic illness as *very severe* were **more than twice as likely** to have requested significant workplace adjustments than those who had a moderate or severe illness (**68 percent vs 32 percent**). Only **4 percent** of leaders who reported that their illness was *not severe at all* requested any kind of workplace adjustment.

These results highlight the pathway dependency between illness severity and the illness disclosure process. The severity of a person's illness invariably impacts on their ability to attend to daily tasks, including engaging in paid work,

and it is therefore likely to affect how they approach the issue of disclosing an illness in the workplace.

For example, if a leader is suffering from an illness that is causing ongoing physical impairment that limits their mobility, they may feel they have to disclose their illness in order to request appropriate workplace adjustments. In cases when an illness is less severe, the process of disclosure is likely to remain more within a person's discretion.

Therefore, there is a need for organisations to ensure that those who have the greatest need for workplace adjustments, feel safe enough to make these requests without fearing negative judgement or consequences. The inherently long-term nature of chronic illness imposes a significant burden on individuals to ensure that they have strategies and supports in place to continue to manage fluctuations and changing levels of impairment over their life-course.

For organisations, this means understanding that leaders with a chronic illness may need to renegotiate their workplace adjustments throughout the employment cycle. The process of disclosure, therefore, needs to be understood as one that is recurring.

"Sometimes it makes people feel sorry for me and that's not what I want."

- research participant

About this Survey

How this study was conducted

In 2020, we conducted a survey study of 326 leaders with a chronic illness to help understand illness disclosure behaviours in the workplace, specifically targeting those who occupy positions of leadership in organisations. With the help of a market research company, the survey was distributed via email to employees based in Australia and New Zealand. We included questions that screened out all participants that were not in leadership positions and did not have at least one chronic illness.

Survey participants were given the following definition of a chronic illness: "A chronic illness refers to a health condition that is persistent and requires some degree of ongoing management. It includes conditions such as arthritis, asthma, cancer, diabetes, hypertension, anxiety, depression, etc." The market research company controlled the identity of the participants to avoid any false or double registrations. We further included test questions and screened out participants that did not respond appropriately to these questions.

Survey measurement

The participants responded on a five-point Likert scale ranging from 1 (e.g., strongly disagree) to 5 (e.g., strongly agree). Depending on the question and statement, we used different response anchors such as strongly disagree to strongly agree, not at all to full extent, never to very often, not accurately at all to extremely accurately, and not at all important to extremely important.

We have used well-known and validated measurement scales of previous research to measure the different variables in our study such as illness disclosure behaviour, perceived stigma about chronic illness, psychological safety, organisational support, and trust in supervisor[xi].

To improve the presentation of the findings for this report and to facilitate the understanding of the results, we transformed the measurement of the five response categories (based on the 5-point Likert scales) into three response categories. For example, we grouped response category 1 to low (e.g., not severe at all), response categories 2 and 3 to medium (e.g., moderately severe), and response categories 4 and 5 to high (e.g., very severe).

Survey population characteristics

Sample Description
The 326 leaders occupied different management positions: executive/top management (14 percent), senior management (22 percent), middle management (42 percent), lower management (15 percent), and frontline leader (7 percent). The leaders all worked all in different organizations and industries in Australia (70 percent) and New Zealand (30 percent). In total, 141 employees (44 percent) were women. The sample represented a diverse age distribution: 18-29 years (12 percent), 30-39 years (24 percent), 40-49 years (23 percent), 50-59 years (23 percent), 60-69 years (17 percent), and older than 69 years (2 percent).

Nature of chronic illness
Respondents were asked to specify the chronic illness(es) they had been diagnosed with by a medical professional. The nature of the chronic illness was then categorised as follows: i) mental health, ii) physical health, and iii) mental and physical health.

The survey found that a majority of respondents, 70 percent, reported having a physical health issue only; these included conditions such as arthritis, chronic asthma, musculoskeletal disorders and kidney disease. A further 20 percent of respondents indicated that they had been diagnosed with a mental health issue only, such as depression, anxiety, or bi-polar disorder. Finally, 10 percent of people reported managing both a mental and physical health issue.

Illness severity
respondents were asked to rate how severely they experienced their illness as being on a daily basis. Our survey found that 68 percent of leaders rated their chronic illness as moderately severe, while a further 22 percent indicated their illness was very severe. Only one-in-ten people indicated that their health condition was not severe at all.

Illness visibility
Our respondents were asked to what extent they believed their chronic illness was visible in the workplace. We found that over half of leaders, 53 percent, believed that their long-term health condition was not visible to others, and an additional 40 percent believed their illness was moderately visible. Only 7 percent of respondents indicated that their chronic illness was highly visible in the organisation.

Years spent living with illness
An illness is generally considered chronic if it has persisted for more than six months. However, the reality for many of our survey respondents was that they had lived with their condition for an extended period of time. The survey found that 54 percent of leaders had been living with their health condition for more than 10 years, while a further 23 percent reported that they had been living with a chronic illness for between 6-10 years. An additional 23 percent of leaders had been managing a long-term health condition of five years or less.

References

[i] Australian Bureau of Statistics. (2022). Long-term health conditions. https://www.abs.gov.au/articles/long-term-health-conditions.

[ii] Ruppanner, L., Churchill, B., Bissell, D., Ghin, P., Hydelund, C., Ainsworth, S., Blackhman, A., Borland. J., Cheong, M., Evans, M., Frermann, L., King, T. & Vetere, F. (2023). State of the Future of Work Report 2023. Work Futures Hallmark Research Initiative, The University of Melbourne, Melbourne VIC.

[iii] ibid., p.19.

[iv]Australian Bureau of Statistics. (2022). Long-term health conditions. (Count of Selected Long-term Health Conditions by 1-digit level OCCP Occupation).

[v] Stacey, P. & Sawyer K. (2021). Employment and long-term illness: The invisible Talent Pool. Astriid. UK.

[vi] Ghin, P. P. (2019). The sick body: Conceptualizing the experience of illness in senior leadership. In M. Fotaki & A. Pullen (Eds.), Diversity, affect and embodiment in organizing (pp. 91-110). Cham, Switzerland: Palgrave McMillan.

[vii] Black, E. (2022). Long COVID-19 costing Australia $100m a week. The Financial Review. https://www.afr.com/work-and-careers/workplace/long-covid-19-costing-australia-100m-a-week-20220909-p5bgq1

[viii] Australian Institute for Health and Welfare. (2009). Chronic disease and participation in work. https://www.aihw.gov.au/reports/chronic-disease/chronic-disease-participation-work/summary

[ix] Ghin, P. (2019). The fit, the fat, and the sick leader: Exploring the relationship between leadership and health through the lens of embodiment. Unpublished PhD thesis.

[x] Ghin, P., & Adamovic, M. (forthcoming) Do your colleagues needs to know about your chronic illness? Harvard Business Review.

[xi] Vogt, D., Di Leone, B. A., Wang, J. M., Sayer, N. A., Pineles, S. L., & Litz, B. T. (2014). Endorsed and Anticipated Stigma Inventory (EASI): a tool for assessing beliefs about mental illness and mental health treatment among military personnel and veterans. Psychological Services, 11(1), 105; Kanter, J. W., Rusch, L. C., & Brondino, M. J. (2008). Depression self-stigma: a new measure and preliminary findings. The Journal of nervous and mental disease, 196(9), 663-670; McGonagle, A. K., & Hamblin, L. E. (2014). Proactive responding to anticipated discrimination based on chronic illness: Double-edged sword?. Journal of Business and Psychology, 29, 427-442.