

# Working with chronic illness: the modes of working

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## Bio:

Shalene Werth is a lecturer in employment relations at USQ, whose PhD study was on the topic of the workforce outcomes of women with chronic illness at Griffith University. Her research interests include the impost chronic illness has on the lives of sufferers, and ways collective action can improve outcomes for both workers and students. The ways employers accommodate chronic illness with specific focus on gender and related industrial relations theory is also of interest.

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### ***Abstract***

*The ways that individuals manage their behaviours in the workplace has received increasing amounts of attention since Hochschild's initial work on emotional labour (1983). Since that time aesthetic labour has been explored (Warhurst et al. 2000) and varying forms of emotional labour or emotion work have been researched (Bolton & Boyd 2003). Progressing this area of research into the working circumstances of individuals with chronic illness has unearthed three new modes of working which are based on similar principles to emotion work and aesthetic labour. These are called adaptive work, asymptomatic work and symptomatic work. Working with chronic illness is a unique experience and requires the use of skills beyond those normally utilised in the deployment of emotion work or aesthetic labour. This paper will discuss adaptive work, asymptomatic work and symptomatic work and relate them to the workforce experiences of women with chronic illness.*

### **Introduction**

An increasing number of Australians of working age suffer from chronic illness. 'With ageing of the Australian population and increasing prevalence of some risk factors such as obesity, chronic disease prevalence is on the rise' (Australian Institute of Health and Welfare 2009, p. 1). Chronic illnesses might include such diagnoses as multiple sclerosis, diabetes, mental illness, rheumatoid arthritis or lupus. The difficulties that chronic illness presents to society are reflected in the experiences of people with chronic illness. For example, one participant in this study, details of which will follow, was Claire. Claire was a triple certificate nurse, who had diabetes. When her illness prevented her from continuing to work in her profession, she sought a disability pension. During this process, she was told by a government employee that she was fat, lazy and did not want to work. Claire was forced onto a Newstart allowance (unemployment benefit) which required her to undertake volunteer work at a local school for disabled children. She enjoyed this work because she felt that she was not judged by others due to her size or her illness, and she was able to utilise some of her nursing skills as a teacher's helper. After a period of time, it became evident that her symptoms, which had been attributed to her diabetes were changing and she was ultimately diagnosed with a brain tumor. Claire has since passed away. Claire's situation was particularly poignant but the disadvantage she experienced is not unique.

Most research on chronic illness has attempted to investigate the nexus between the manner in which society treats those with illness and the subsequent reactions of those with illness (see Barnes 2000; Bury 2002). Little research has focused on the situation of chronically ill people at work, especially in relation to the way they engage with those in their workplace, and the way they cope with the regulatory environment. Research that expands on these areas is needed because there is a link between chronic illness and labour market participation. According to the Australian Institute of Health and Welfare, 'People with chronic disease were 60 per cent less likely to participate in the labour force, were less likely to be employed full-time, and more likely to be unemployed, than those without chronic disease' (Australian Institute of Health and Welfare 2009, p. 1). It would be expected that if chronic illness has an impact on participation and unemployment rates then it would also affect experiences at work. Indeed, the apparent impact of chronic illness on participation rates may be a reflection of what happens in the workplace. This needs to be better understood.

## **Literature review**

Literature which examines the way people behave when they have a chronic illness is drawn from a number of disciplines, including sociology (for example, Goffman 1963, 1986) and business (for example, Vickers 2009) although research might also originate in other fields such as nursing (for example, Pinder 1995). In their work environment, people with chronic illness, may be assessed on the basis of their illness, rather than on the basis of the knowledge, skills and abilities they bring to the organisation. There are a number of existing behaviours in the literature relating to the workplace which pertain to managing illness in social settings. Passing, covering, and emotion work, amongst other concepts, each contribute to the discussion on the normalisation of behaviour of those with potentially discreditable identities, including those with chronic illness. Goffman first identified the concept of passing and defined it as ‘the management of undisclosed discrediting information’ (1963, 1986: 42). Since then other writers have explored the concept and found the range of behaviours involved in passing may include deliberate concealment (Myers 2004), misrepresentation of the self to project conformance (DeJordy 2008), discretion (Herek in Clair et al. 2005), or simply the avoidance of the revelation of any ‘discreditable invisible identity’ (DeJordy 2008: 508).

Goffman also pioneered thinking on the concept of covering, commenting, ‘it is a fact that persons who are ready to admit possession of a stigma [such as a chronic illness] may nonetheless make a great effort to keep the stigma from looming large’ (Goffman 1963, 1986: 102). DeJordy added to this, commenting that covering is ‘engaging in normalising behaviour despite having revealed a stigmatized identity’ (2008: 513). Myers used covering to mean ‘an attempt to downplay a condition after disclosure’ (2004: 261).

According to Hochschild, emotional labour ‘requires one to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others’ (1983: 7). DeJordy (2008) explores emotional labour in relation to invisible social identities including chronic illness. He lists emotional labour as one of a number of constructs which may be used to misrepresent the self in order to project conformance and shows that it forms part of the behaviours deployed by those with chronic illness. Another related construct, sometimes used interchangeably with emotional labour but generally treated as distinct, is emotion work. Bolton and Boyd describe emotion work as ‘presentational emotion management’ (2003: 291). Emotional labour most commonly refers to the type of labour which is required as part of a paid work role, while emotion work appears to align more closely with the type of work undertaken by those with chronic illness.

Often individuals with chronic illness also need to disclose their illness within their workplace due to treatment options or because they need to access flexibilities at work to cope with the circumstances of illness. It may not be a positive experience because they then have to manage the perceptions of others in terms of their capability at work. They may be considered to be ‘not suitable’ in their line of work or they may be told that they need to find work more suited to their abilities. Chronic illness has the potential to influence an individual’s ability to do their job in organisationally expected ways, however allowances could be needed from time to time to allow for the contingencies of an individual’s illness (Myers 2004).

### *New concepts: Adaptive work, asymptomatic work and symptomatic work*

Adaptive work, asymptomatic work and symptomatic work, as distinct concepts, emerged from this study on the experiences of women with chronic illness in their places of work (Werth 2013). Individuals with on-going or chronic illness have been identified as a group with stigmatising characteristics (DeJordy 2008). This group undertake adaptive work, asymptomatic work or symptomatic work to manage both their work and the circumstances of their illness. After an illness has been disclosed in a work situation, the individual may then seek some form of adaptation which would enable them to continue working while managing their illness. Adaptive work is defined as ‘engaging with others in the workplace in order that they, or the organisation, adapt in some way to meet the needs of those with chronic illness’ (Werth 2013, p. 47). These adaptations may take the form of social accommodations such as achieving understanding or a change in attitude from others at work, or formal accommodations which might consist of general or contingent flexibilities, such as sick leave, adjusted hours of work or a physical adjustment within the workspace.

Asymptomatic work is defined as: ‘the behaviours used by women or men to carry out their responsibilities at work without the appearance of symptoms associated with a chronic illness’ (Werth 2013, p. 47). It includes managing symptoms, attitudes and behaviours of the individual, prior to disclosure, so that they are able to maintain a capable appearance in their place of work. Symptomatic work is the ‘undertaking of work responsibilities while symptoms are apparent’ (Werth 2013, p. 47). It involves the management of physically obvious symptoms to preserve the individual’s professional capability. Symptomatic work is a practice which attempts to mesh the support of medical intervention with the culture and requirements of a workplace.

### **Methodology**

Participants were sourced, using a snowballing technique through support groups for chronic illnesses, networks of support services and union newsletters to facilitate a greater spread of characteristics such as type of employment, level of position and pay. Interviewees were employed in a variety of occupations, including town planners, engineers, cleaners, waitstaff, nurses, teachers and managers with varying levels of responsibility. Twenty-four participants agreed to be part of the research. Their ages ranged from 20 years to over 60 years of age, and they came from a variety of places within Australia, including Perth, Sydney, Brisbane and regional Queensland.

Individuals with chronic illness form a population which is largely invisible and difficult to access, for this reason a snowballing technique was used to find participants (Atkinson & Flint, 2001). This was effective in finding participants from regional and non-regional areas, it was also useful in accessing a variety of illnesses, including various forms of arthritis, diabetes and mental illness.

Participants were interviewed using a semi-structured format, these were recorded with the consent of the interviewee and these recordings were transcribed verbatim. Questions asked related to topics such as details of diagnosis, impact of illness on actual work and working conditions, disclosure, details of work, union membership, work history, illness history, attitudes to working with illness, and demographic data. Themes were extracted from the

transcriptions and detailed analysis of the data was undertaken using NVivo8. Ethics approval was granted for the project.

### **Results and Discussion: modes of working**

The implications of chronic or on-going illness are different to those of other types of invisible social identities. The difference is evident in the variability of symptoms. The potential for sudden onset, re-emerging, changing or worsening symptoms may create issues where individuals are required to disclose. Changes in symptoms may require that workers behave in particular ways in order to access understanding and/or accommodations or to avoid disclosure to assist with circumstances related to illness in their workplace. Outcomes of this research include the development of three new concepts as applied to work in these contexts, adaptive work, asymptomatic work and symptomatic work. These modes of working reflect the different behaviours exhibited by participants in their workplaces in order to manage perceptions of supervisors and colleagues.

#### *Adaptive work: the concept*

Adaptive work is how individuals with chronic illness engage with others in the workplace in order that they, or the organisation, adapt in some way to meet the needs of women with chronic illness. It may be undertaken by those who require some adaptation or accommodation from their workplace to assist with managing their work and their illness (Werth 2013). Workers with chronic illness may, after disclosure, seek understanding as well as social and formal accommodations to assist with their circumstances of illness at work (Vickers 2001). Understanding refers to the positive attitudes to their illness which occur separately from the receipt of any accommodations. Social accommodations are adjustments made by colleagues and management in their attitudes and social interactions with people with chronic illness. Formal accommodations consist of contingent or general flexibilities and are associated with an organisation's rules (Werth 2013). As disclosure is often facilitated by an exacerbation of illness, seeking understanding and some form of social and formal accommodations is likely to follow. The flexibility or accommodations that these workers seek are employee friendly flexibilities, not the flexibility that employers seek from their workforce for the sole benefit of the organisation (Vickers 2010). However, the flexibilities referred to here are those which allow individuals with illness to continue working despite their illness, and these flexibilities may also benefit the culture of the organisation.

Those with chronic illness may be concerned about the degree to which they are able to access accommodations at work to assist them in achieving work related outcomes. Managers may prefer to demand that individuals take sick leave and not return to work until they are well (Parsons 1970), which creates difficulty for individuals with chronic illness who cannot be sure when they will improve (Myers 2004). Employers have the potential to present a more compassionate response to the circumstances of their staff, however research has shown that this type of understanding cannot always be expected (Vickers 2009). Disadvantage may be experienced by workers through the perceptions of others which:

...include assessments of the [chronically ill] individual's 'deservingness' of accommodation and implications of the visible symptoms of the disease, predictions

of whether or not chronically ill women will be capable of full employment in the future, and appraisals of their suitability for their chosen professions (Jung 2002: 193).

The social influences experienced in the workplace significantly impact on the successful deployment of adaptive work.

To achieve accommodations for illness, those with chronic illness will attempt to adjust their circumstances at work. Illness and subsequent work outcomes become catalysts for 'decisions, tactics and organisation of work carried out over the trajectory of the illness' (Gerhardt 1989: 147). Individuals may request assistance with their circumstances of illness from their supervisors. These requests may be straight forward sick leave requests which do not require particular consideration for the chronic nature of the illness, known as general flexibilities and which are available to all workers. They may also take the form of requests for ongoing flexibility which might not fall within the normal guidelines for provision of leave, known as contingent flexibilities. Adaptive work requires agency for women to put forward their case. Labour market power contributes to the success of adaptive work. The ability of women to successfully negotiate for contingent flexibilities is, at least in part, dependent on their labour market power. Labour market power is influenced by the employer's ability to access alternative workers (Peetz 2007), level of position, length of service with the employer, permanence of position, education and skill level of the employee. While internal labour market power is influenced by specific skills and abilities associated with a particular organisation or position, these are contributing factors to the success of adaptive work.

High levels of external or internal labour market power help to mitigate the difficulties associated with working with illness. Pinder highlights some of these difficulties of managing the way that individuals with disability (including chronic illness) appear at work:

What disabled people are faced with at work is the task of establishing trust or repairing trouble, which in turn highlights the differential ability of individuals to persuade employers to 'run with' ambiguity and disturbance, and of organisations' [ability] smoothly to dispose of it: one of the classic tensions of contemporary life (1995: 607).

Adaptive work is underpinned by the fact that organisations and supervisors may have particular expectations for the employment of individuals with chronic illness. Bury makes reference to the disruptive nature of illness and 'the issues involved in the active responses people fashion in social interaction' (2002: 12). However, adaptive work goes further and provides a framework for the type of work required when seeking the accommodations or adaptations needed by the individual in their workplace. Adaptive work is composed of a selection of deliberate behaviours and the success of requests for adaptation may be influenced by a variety of factors including labour market power, social rules and organisational policy. Adaptive work will be further discussed now as it emerged in the data.

#### *Adaptive work and women in their workplaces*

Mary disclosed her illness to the Board of her organisation in order to gain their support for her unusual working situation. Due to the expensive nature of the treatment that Mary undertook a number of times each week, it was important that she was able to retain her

Health Care Card. A change in legislation decreased the number of hours she was able to work and still keep her Health Care Card. Mary negotiated with her Board to undertake part of her employment as paid work and the remainder of her full-time position was unpaid work. The Board agreed and, as a result, Mary worked full time but was paid for 29 hours per fortnight. She commented that:

There were several [Board] members who said, 'It's too much.' But I came on board here to rejuvenate the Centre, which is what I do in my positions, I move them forward and this one was in big need of it.

The adaptive work that Mary utilised to request adaptations was quite extraordinary. It was based on her professional competence, her personal preference for full-time work and goal oriented personality as well as the internal labour market power associated with her role as manager of the Centre and the external labour market power derived from her previous working experience. The combination of these factors meant that she had the confidence that she needed to successfully negotiate with her Board for the adaptations she required.

Heather used adaptive work in her employment. She was diagnosed with rheumatoid arthritis when she had an initial flare which required her to take time away from work in order to stabilise her condition. Heather described her negotiations with her boss regarding her return to work thus:

It was a bit of an effort to try and convince him that all I needed was a bit of patience with the physical. I didn't need to be pitied and pandered to in terms of anything else. Just needed a little bit of time to get my body back into action.

She felt that his concern related to her ability to manage her job at senior management level on reduced hours, in order to stage her return to full-time work.

I initially came back three days a week and I lasted doing that for about a month and a half and then I went four days a week. And I think there was some concern that I wouldn't be able to perform the duties of the task in that period of time, that in three or four days a week I wouldn't be able to achieve what needed to be achieved. So it took a little bit of convincing to assure him that I'm a hard worker. [I said to him] 'You get more out of me three or four days a week than you'd get out of the average Joe Blow in five days a week. So just let me prove that I'm up for this and we'll go from there.'

Heather's negotiations regarding her return to work were extensive and showed how she used adaptive work in her arguments for a change of her working hours and of the work itself. When Heather was working three days each week her role was shared by someone else, but when she returned to work four days each week she undertook sole responsibility for her whole job.

I did most of [the job] on three days a week, but what I didn't do was the staff management responsibilities... What I took on was all of the complex and controversial decision making responsibility and one of my colleagues took on the supervision of staff responsibilities. But when I went from the three days to four days I took on everything. So, I was essentially doing 10 hours a day for the four days a week. So I was for all intents and purposes working full-time. It just gave me that extra day for recovery I suppose.

Heather continued to use adaptive work after her return to work. She negotiated with her boss for periods of 'timeout', when she needed a break if she was not feeling particularly well. She also had strategies in place for managing the reactions of her staff when they were less than understanding. To do this Heather exhibited agency through self-reflectiveness in her adaptive work through her 'ability to construct appropriate courses of action and to motivate and regulate their execution' (Bandura 2006: 165). Heather adjusted her work according to her symptoms and was able to construct and execute appropriate courses of action which enabled her to manage her work, her boss and colleagues. Heather also showed intentionality when she developed a strategy for her periods of time-out and when she staged her return to work. The success of the adaptive work displayed by Heather was influenced by the level of her position, the credibility she had in her workplace, due to previous employment in her department, and her negotiation skills.

Adaptive work, as utilised by Samantha in her position as a waitress in a coffee shop, was used in one circumstance where she and her flatmate were encouraged to find other work because of their illnesses. The adaptations they sought were concerned with receiving understanding for their illnesses.

A friend of mine also had type 1 diabetes and we lived [and worked] together at the time. They pulled us up one morning tea on an eight hour shift when there was a break in the customers coming in. The duty manager sat us down and said, 'Look we're not happy with your work. Both of you are unreliable and we'd like you to find positions more suited to your needs.' After that they dropped our hours. My friend's mother got two solicitors and dragged them down to the [Company] and they said [to the owners], 'There's no need for this, they've always told you that they've had these problems. When they're sick they're sick, they're not hungover, they're trying.' We were doing seven days straight. And what they were meant to be doing was giving us 12 hours notice of a change of shift, but they didn't. They were just ringing us up five minutes after we finished a shift and saying 'Can you come in tomorrow morning?' So we'd finish at 11pm and have to be there at 7am the next morning, after an eight hour shift [the previous day]. It was highly strenuous work, the conditions at the store at the time weren't great... So we got our shifts back and got our hours back, much to their disgust.

Samantha did not, individually, have the labour market power to ensure that she would be successful if she sought adaptation in her work environment, particularly one where there was no understanding or allowances made for the specific difficulties of her diabetes. Individual agency and power in negotiation did not have any significant influence on her employers. The adaptations were achieved through legal assistance from outside and the support of friends. The power relationships that Samantha had through her friend's mother enabled her to access adaptation, an adaptation that was legally required of her employer.

Samantha needed accommodations or understanding in order to stay well. Sufficient rest between shifts was important for Samantha and this was also difficult for her to access, but a more significant issue was the discrimination she experienced because of her illness. Denial of the requests of these women could have resulted in an exacerbation of illness and they could have brought a case, under occupational health and safety legislation, against their employers. These examples of the way social rules and organisation policy were applied to

the requests for adaptations show how women with illness at work continue to be subjected first to normative social expectations of what it means to work with an illness before their employers' legal requirements were considered.

The need for individual women to access basic adaptations required increased agency. These might include the ability to take breaks or holidays, or be allocated a reasonable workload in order to prevent illness. Most of these basic requirements should be provided as a matter of course as they are legal rights of workers. Women who have a lesser amount of labour market power are more vulnerable and more likely to be denied their basic rights (Werth 2013). However, it also seems that even women who have a reasonable amount of labour market power may also be disadvantaged because of the attitudes of supervisors, particularly related to social rules, and even where there are policies in place to protect them, they might choose not to complain. Samantha, at times, chose to leave positions rather than 'fight' the disadvantage she experienced at work. And even if these women were willing to argue the case, they also needed to consider the impact it would have on their health. Alternatively, Mary and Heather who were both very senior within their organisations were able to argue for the accommodations they wanted and were successful. Employees with the highest level of labour market power were able to seek adaptations that assist them in the management their work and their illness.

The key function of adaptive work is to seek adaptation which allows for illness in the workplace (Werth 2013). For some women the adaptations they sought should have been a legal right, but these were not always made available. Adaptive work may also be used to access contingent flexibilities for making their work more manageable and accommodating for the circumstances of illness. Labour market power proved to be important to women with chronic illness in the success of their requests for adaptation. The main focus of those deploying adaptive work was to protect their employment and to provide them with a good working environment. The main focus of adaptive work was to request accommodations which enabled women with chronic illness to better manage their illness in the workplace. Adaptive work is a significant concept as it describes the range of behaviours deployed by those with illness in an attempt to manage information, appearances and reactions of others when attempting to access accommodations.

#### *Asymptomatic work: the concept*

Asymptomatic work is defined as: 'the behaviours used by women to carry out their responsibilities at work without the appearance of symptoms associated with a chronic illness' (Werth 2013, p. 47). It includes managing symptoms, attitudes and behaviours of the individual so that they are able to maintain a capable appearance in their place of work. Asymptomatic work is carried out in instances where the individual with chronic illness has not previously disclosed (Werth 2013). The main objective of asymptomatic work is to enable the individual to appear normal within their workplace. It also involves the assessment of the attitudes of others and the organisation to those with illness. This includes an assessment of the culture or workgroup of the organisation. Individuals make an effort to determine: How many sick days may be acceptable? Or, how sick is one able to be before drawing attention to the possibility of the existence of an on-going illness? Asymptomatic work may occur prior to

the diagnosis of an illness, where symptoms are sufficiently mild and are able to be hidden. It may also be deployed after diagnosis, when a decision has been made not to disclose (Werth 2013).

Asymptomatic work is more than merely passing. Passing is defined by Goffman as ‘the management of undisclosed discrediting information about self’ (1963, 1986, p. 42). DeJordy adds to this that ‘an individual may pass by not revealing [their identity] at times’ (2008, p. 508). Asymptomatic work also involves agency in the purposeful gathering of information regarding the attitudes of others, so that individuals may assess the reactions of others should they need to disclose when there is a change in their severity or progression of their illness (DeJordy 2008; Vickers 2003; Werth 2013). Asymptomatic work is different because workers with chronic illness are proactively involved in the interaction with their work environment regarding their illness to allow them to continue working. There is also a more subtle difference between passing and asymptomatic work that is attributable to the involvement of chronic illness. The symptoms of many types of chronic illness wax and wane (Myers 2004). There is however, in many cases, an inevitability associated with an illness becoming difficult to conceal. The agency that workers employ in gathering information about their workplace is more than just preserving how they will conceal information at a given point in time. It is also designed to assist in preserving the appearance of capability in their workplace into the future, should they need to disclose.

#### *Asymptomatic work and women in their workplaces*

Asymptomatic work may be employed for a variety of purposes, such as enabling women to appear normal in the workplace and avoid disclosure or stigma. It also focuses on responding to the expectations of the workplace. For example: some sick days will be expected; headaches may be construed as normal muscle soreness may be attributed to a recent sporting incident or similar ‘normal’ activity. It is important that these do not happen often enough so that they put the individual under suspicion of malingering. Understanding the requirements of the individual’s employing organisation, appreciating the expectations which colleagues have of each other and observing the impact that illness information has on others, assist in shaping the asymptomatic work used by women with chronic illness.

Asymptomatic work enabled Emily to avoid disclosure of an embarrassing and potentially stigmatising illness in her workplace. Emily had Crohn’s disease and she related some of the difficulties of managing a digestive disorder in her workplace. She commented that she was conscious of the time she spent away from her desk when she needed a bathroom break, but had no real way of covering this evidence of her illness. One way to maintain her appearance of capability, she felt, was to improve her performance. Working late was a strategy she employed to maximise her productivity. This was significant because she reported that she often felt very tired, and she believed this interfered with her work:

I feel I’m not performing as well, and mentally that makes you feel a bit sad or whatever. Occasionally there have actually been a few times when I have just felt, unwell, and I just think I wish I was at home, I can’t even perform as well. I wish I could go home, or just go and have a sleep for a while, and I mean you can’t. But I

guess that's when I really notice it, I just wish there was a bed around the corner, a little bed cubicle in the office.

Emily's asymptomatic work meant assessing the possible reactions of others. A stigmatising illness makes the self-monitoring of behaviours, the manner of undertaking work tasks and successful asymptomatic work, high stakes activities. This is particularly the case when an illness could stigmatise the worker. Emily chose not to disclose.

Emily managed her illness through the use of non-contingent flexibilities.

I do have day procedures about four times a year, and I always know when they're coming up. I tell my boss I've got to have a couple of days off and I can supply a medical certificate and he's happy with that.

As Emily complied with workplace policies relating to sick leave, she was able to keep her illness from becoming known to others. In this way, conforming with policy formed part of her asymptomatic work. She noted that she had missed out on site visits associated with her work, and while she would have liked to participate in these she was wary that they could force her disclosure. Asymptomatic work for Emily required that she manage her symptoms, complied with workplace requirements for taking sick leave and worked additionally in order to preserve her appearance of a capable worker. Emily's non-disclosure meant that she was unable to use her labour market power to achieve better working outcomes. This is because disclosure in addition to labour market power in certain contexts has potential to facilitate understanding and support from supervisors.

Louise also deployed asymptomatic work in order to avoid disclosure. The asymptomatic work that Louise employed was specific to particular groups of individuals in her workplace. She was in the unusual position of going back to work in her old workplace in a lower level position after some years away from work because of Chronic Fatigue Syndrome. Some colleagues with whom she had worked previously knew that she had issues with her health when she resigned, but she still preferred not to disclose to those who did not know.

They're aware that, when I had to finally resign [from the former position] that my illness was the major problem, but I didn't really say too much.

She pointed out that she did not go into detail or disclose her illness to colleagues with whom she had not worked before.

The others in the working group that are new to me, I haven't said anything [about my illness].

Louise managed her work and the way she appeared to others, by working late to make up for the extra time she might take to do some tasks.

I get into 'trouble' now because I stay back. You're not supposed to [but] I'm not worried about overtime, if it takes me half an hour longer to do something. Then of course it reflects on the other staff because I'm in an open office area.

Balancing her personal need to do a job well, but not wanting to make other staff look like they are not trying hard enough, formed a part of the asymptomatic work that Louise employed. She juggled the way she appeared to those who knew about her health, and those who did not. She also had to manage her own expectations.

I've got to get used to that, when you're supposed to go [home] you just [say] 'If it's not done, there's always tomorrow.' But that's not how [I] work.

Part of managing the impact of her illness on herself and her work was to use practical strategies even outside her workplace, such as going to bed early.

There are times when [I've] got to say 'Ok, going to bed, 8.30pm, see you in the morning,' and just manage it that way.

Asymptomatic work for Louise was similar to that employed by Emily. They both worked over and above what was required of them to preserve the way they appeared to others and they hoped to avoid disclosing when they preferred not to. Part of Louise's experience was that her immediate supervisor, to whom she had not deliberately disclosed but who may have known of her health issues from other sources, really did not want her to work the additional unpaid time that Louise felt was necessary. In this circumstance, managing the perceptions of others proved to be an issue for her at work which influenced her use of asymptomatic work.

### *Symptomatic work: the concept*

Symptomatic work is 'the undertaking of work responsibilities while symptoms are apparent' (Werth 2013). It involves the management of physically obvious symptoms to preserve the individual's professional capability. Symptomatic work is a practice which attempts to mesh the support of medical intervention with the culture and requirements of a workplace.

Parsons' (1970) consideration of rights and responsibilities for those with illness still apply in organisations but tend not to fit the circumstances of chronic illness (Myers & Grasmick 1990). Perceptions of professional capability expected by workplaces might also involve specific ways of working. To complete a task in different ways may not be desirable by that organisation. Thus managing one's appearance of professional capability for those with chronic illness might be challenging. Understanding of social expectations is important for those with chronic illness, particularly as these individuals need to develop ways of projecting an image of ability in the workplace despite having physically obvious symptoms, assistance aids or treatments which require time away from work (Goffman 1986).

Symptomatic work requires agency but in different ways to that of adaptive work. The agency in symptomatic work is directed towards medical professionals and the management of symptoms - either before or after diagnosis. Individuals skilled in symptomatic work might use social expectations, such as Parsons' (1970) requirement that sick individuals should receive understanding while they receive appropriate medical treatment, to gain some latitude from their workplace while they seek a diagnosis. Symptomatic work provides an opportunity to use personal and professional skills such as sharing information and working exceptionally hard, to preserve an individual's professional integrity in work situations (Werth 2013).

### *Symptomatic work: women in their workplaces*

Symptomatic work is 'the undertaking of work responsibilities while symptoms are apparent' (Werth 2013). Symptomatic work may be more socially difficult than asymptomatic work, particularly if a diagnosis is not yet available, and the symptoms have no known cause or where symptoms are physically obvious. A diagnosis provides legitimacy for symptoms (Vickers 2001). Working with symptoms with no diagnosis can be difficult and may result in

workers being labeled as malingerers as there is no medically supported reason for the apparent illness of the individual. Depending on the stigma (Goffman 1986) attributed to the disease, a diagnosis may not improve the situation, thus the preservation of a capable professional image may be difficult both before and after diagnosis depending on severity of symptoms and available accommodations (Vickers 2012). Where there is a supportive work environment individuals may be able to continue working even with reasonably difficult symptoms. However, any substantial difference between offered accommodations and severity of symptoms will determine whether an individual with illness is able to remain in their position (Vickers 2012).

Melanie suffered from on-going joint problems, the cause of which had not been diagnosed.

It's had all kinds of different names, rheumatoid arthritis, fibromyalgia all kinds of things and then when it doesn't progress, [the doctor is] not really sure. So I just get monitored, all the blood tests, one thing I think [the doctor is] expecting me to get is lupus. She tests me for lupus every year. I was diagnosed with glioma in the brain, [some time ago] that was one of three things, they were monitoring me for quite a few years afterwards for MS. The latest diagnosis is that it's a one-off MS episode.

The support Melanie had received in her workplace meant that the additional symptoms, for which she had no firm diagnosis, were not considered to be a problem. However, in a previous workplace, she had suffered what was later diagnosed as a one-off multiple sclerosis episode. She commented that she tried to return to work afterwards, but the 'anti-seizure medication... impacted on everything.' She reported saying, 'I just can't cope with work anymore.' She left the workforce for 12 months, after which she decided that she wanted to 'get [her] life back.'

I hadn't had any seizures so I went to the doctor. And he said, 'Well, we'd really like you to stay on the medication.' I said, 'I don't want to because there's just no quality of life.' It was just awful.

In this situation, Melanie had an uncertain diagnosis and was not able to continue working because of her medication. This resulted in her departure from the workforce for a period of time.

There was a point, for some participants, where accommodations were insufficient to assist with continued work or where their illness was too severe to continue in the workforce. This does not preclude them from returning to the workforce, perhaps in a different work environment, when their symptoms subside or their illness is better controlled. In her most recent role, Melanie had developed ways of managing her illness and her work. She was in a position where she was able to access adaptation through adaptive work and she managed the way her symptoms had an impact on her professional capability through symptomatic work appropriate to her supportive work environment.

Lucy was not given the opportunity to deploy asymptomatic work as she needed to disclose after a severe, initial onset of Crohn's disease. She was diagnosed after a number of weeks in hospital. Upon her return to work she was not provided with the understanding she needed to continue her career in that workplace, so she resigned. Lucy's illness was one which could be stigmatising, and this may have contributed to the lack of understanding she received. A combination of symptomatic work and adaptive work was not sufficient for her to continue

her career in that workplace. The lack of support available at work and the difficulties of working with chronic illness were too great for her to continue her career there. She subsequently returned to the workforce after studying and worked in a different profession. Her new role provided her with the understanding and accommodations she needed to have a successful career. Lucy moved very quickly from pre-diagnosis symptoms and symptomatic work, to needing to leave that workplace, due to a flawed evaluation of her value as an employee because of her illness. In comparison, Heather was able to effectively deploy work to remain in her workplace.

Stigma, preservation of a capable image and severity of symptoms are factors which influence the performance of symptomatic work. Individuals with illness have little choice regarding disclosure when their symptoms become obvious. At this point, the perceptions that others hold about illness might result in an assessment of the worker based on their symptoms rather than the actual abilities of the worker with illness. Symptomatic work involves attempting to preserve one's appearance of capability while working and managing obvious symptoms.

### **Conclusions**

The women in this study displayed the propensity to employ agency to change their circumstances in order to manage the sometimes conflicting requirements of their workplace and their illness. The concepts of adaptive work, asymptomatic work and symptomatic work were developed specifically to describe the behaviours of individuals with illness. Deploying these modes of working provides a way to offset the disadvantage of working with a chronic illness. The data highlighted the difficulty experienced by these women with chronic illness in the management of physical symptoms, social expectations and perceptions of a capable worker. The modes of working were utilised to offset stigma, difficult symptoms and negative perceptions of illness. They also were used to preserve the appearance of professional capability.

Social rules and processes dictate that individuals with an illness have certain rights and responsibilities which should be undertaken to manage their own illness. It is these commonly accepted social rules and processes by which women with illness are judged when they exhibit symptoms of illness in their workplace. Despite the fact that the illness may not affect the individual's ability to perform their work, judgments may be made based on social expectations which project perceptions of inability on the individual with illness. The modes of working enable workers to manage the social difficulties associated with working with a chronic illness.

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