

September 2014



**THE WORK
FOUNDATION**
PART OF LANCASTER UNIVERSITY



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EXECUTIVE SUMMARY

Self-management of chronic musculoskeletal disorders and employment

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Executive Summary

This study considers the self-management of chronic musculoskeletal disorders (MSDs) in the workplace. Self-management can be defined as an individual's ability to manage the symptoms, treatment, physical, social and psychological consequences of living with a chronic condition. Self-management can empower individuals with a better understanding of, and control over, their symptoms and provide them with the tools to ensure their condition is understood and accommodated by others. Work can have social, psychological and economic benefits for an individual living with an MSD, as well as economic benefits for wider society, underlining why it is important to research the underexplored relationship between self-management and the workplace.

The research consisted of interviews with individuals living with a chronic MSD who were either in work, or planned to return to work in future. **The study offers two important contributions to our understanding of self-management and work. Firstly, it offers an insight into self-management at work, and the processes and components that contribute towards fostering or undermining successful self-management. Secondly it offers a view of work as a form of self-management, whereby partaking in work was an important way in which individuals managed several (often psychological) aspects of their condition, albeit often not without compromising the management of some of the physical symptoms of their MSDs.**

It was found that individuals are currently for the most part responsible for achieving satisfactory self-management in the workplace when other stakeholders (including, employers, line managers, healthcare professionals and government) could contribute more. In turn individuals are making compromises such as stalling their career progression or foregoing a social or home life in order to continue working. These compromises, and the pressure which individuals find themselves under to self-manage without adequate support are made all the more perverse when one considers the role that work has to play in contributing to the management of an individual's mental wellbeing. If the benefits of work as self-management are to be truly realised, then the way in which self-management at work is supported needs to be significantly improved.

A **summary of the results** from the interviews follows. Firstly self-management was discussed more generally:

- Most participants had a high familiarity with the concept of self-management, understanding it to mean having control over one's condition and not becoming

overwhelmed by it. Self-management was also constructed as a gradual process, whereby competency to self-manage developed, and could also fluctuate, over time.

- The nature of the individual and the nature of the condition had a bearing on self-management. Some individuals conceived of the management of their condition as a 'fight', while others spoke about approaching the condition with a positive attitude, or 'getting on with it'. Specific aspects of the condition, including the way in which the disease course is unique to each individual, and that the first onset of symptoms are often very hard to control before appropriate medication is being received, had implications for how the disease was managed. The symptoms of pain and fatigue were cited as being key for keeping under control, while it was also noted that the often invisible nature of the condition increased the difficulty of self-managing successfully.
- Participants discussed the many ways in which they gathered information to assist them in managing their condition. Medical professionals, patient organisations, and the internet were key sources of information. Participants discussed general self-management techniques, which included learning one's limits, pacing oneself, resting, appropriate exercise, and making mental adjustments to living with a chronic condition. All of these were underpinned by the need for an effective drug regime.

The interviews then also explored self-management in the workplace in more detail:

- The size and type of organisation that the participant worked for was instrumental in facilitating or impeding self-management. Larger organisations were found to have better support structures in place, while smaller organisations often lacked the necessary resources to support individuals. Public sector organisations also tended to offer more support than private sector organisations, which were often construed as being primarily motivated by profit. There were many participants who were self-employed, an option which was seen as hugely advantageous because of the control it offered the individual over their working pattern and therefore their condition.
- External bodies such as trade unions, occupational health, and government funded initiatives could often provide the catalyst for adjustments in the workplace. However, some individuals also viewed these interventions negatively, especially if they had not made initial contact with them themselves, as they were seen as evidence of an employer believing an individual was not coping in their current role.
- The role of line managers was very important. Individuals reported varying degrees of awareness among line managers. The relationship between the line manager and the

individual was key, as a strong relationship that had developed over time often meant the line manager had a greater degree of understanding, and also that the individual felt trusted and more able to ask for adjustments. Many participants were reluctant to ask for help from their line managers, citing the key reasons as being fear of negative judgement and fear of job loss.

- In general participants found their colleagues lacked awareness about MSDs. Linked to this there were varying degrees of disclosure to colleagues. The sentiment was expressed that participants did not want to be singled out as different to colleagues.
- The various adaptations in the workplace are outlined in a table on page 76. There were examples of where a participant's employer had reneged on promises to provide adjustments. Other participants had not asked for adjustments, perhaps because they were wary of doing so. There were also examples of individuals who felt they could not request a specific adjustment because they had made another request in the past, or planned to make another in the future, suggesting they considered their employer as having a finite amount of support to offer.

Below are a **summary of the recommendations** organised by the stakeholder group they are addressed to. For the recommendations in full, please see page 85 onwards.

The Individual.

- Appreciate that understanding how to manage your condition at work takes time.
- Realise that others have a role to play in managing your condition.
- Equip yourself with information that will help you to manage your condition in the workplace and share it with others.
- Be 'Solutions-focused' and recognise that you may have to take the lead in some conversations with your manager.

Government.

- Increase awareness of and participation in Access to Work.
- Provide extra assistance for employees working in small organisations.
- Invest in more Specialist Nurse roles.
- Ensure work is considered a clinical outcome by healthcare professionals.

The Employer.

- Understand your responsibilities as an employer to people with disabilities and long term health conditions.
- Aim to help employees with chronic MSDs to feel a valuable and mainstream part of your workforce.
- Educate your workforce about chronic conditions.
- Foster career progression options for individuals with MSDs.

The Line Manager.

- Work to build a good relationship with an employee living with an MSD.
- Be proactive: seek out information about MSDs, and be proactive in asking how the employee can be supported to do their job.
- Consider mental as well as physical health.
- Ensure that you take opportunities to praise an employee with an MSD when they have performed well.

Colleagues.

- Educate yourself about chronic conditions.
- Understand that people with MSDs may need to work in different ways to you.

Healthcare Professionals.

- Be aware of the wealth of information you have about condition management and share it with your patients.
- View it as part of your role to ask patients about their work lives.
- Understand that you are crucial in establishing a stable foundation in terms appropriate diagnosis and medication regime upon which an individual can learn to self-manage.

Patient Organisations.

- Do more to share the wealth of resources and information you have on self-management and employment.
- Support a diverse range of sources from which patients can get advice.
- Increase the dissemination of information to raise awareness among employers and other employees.

Family and Friends.

- Educate yourself about MSDs.

- Appreciate that the time following first symptom onset and diagnosis is likely to be the most challenging.
- Be aware that friends or family members with MSDs may need to make sacrifices in their home or social lives in order to continue working.