

# Executive Summary

# Dementia in the workplace

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The potential for  
continued employment  
post diagnosis.

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# Background to project

As in other European countries the number of older people in Scotland is increasing. Although longer life is a good thing, older age often includes a range of challenges including a growing number of people with long term conditions, one of which is dementia. Recent figures suggest that approximately 84,000 people have dementia in Scotland; this number is expected to double within 25 years. Figures for the UK as a whole show a similar pattern. The recent rise in the state pension age and the removal of compulsory retirement at 65 will result in more people with long term conditions being economically active; however, because dementia is usually thought of as something that happens to older people, little attention has been paid to the opportunities for employment. Not much is known about the experiences of people with dementia who are, or would like to be, working.

Allowing people to work longer may bring financial benefits to individuals and their families, as well as the economy and businesses. However, an increase in the number of older people in employment is likely to have costs as well as benefits. Research shows that there are age-related changes which could affect performance in the workplace. More people working in later life will result in a higher number of people with long term conditions in employment and, while the impact of some long term conditions, particularly those associated with physical disabilities, can be reduced by use of technology and/or a change in role, continued employment for people with dementia poses specific difficulties for those affected and their employers. The changes in pension age mean older people may find their work being monitored more closely as employers can no longer assume that they will leave at 65. However, employers have been found to have little understanding of the impact of increasing age and age-related conditions.

## Aim

The aim of this project was to explore the employment related experiences of people with dementia or MCI, and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis.

# Methods

The project was carried out over two years from 2013-2015. There were three phases of the research designed to explore the potential for continued employment for a people following a diagnosis of dementia.

## **Phase 1- Literature review**

The aim of the literature review was to establish, from a range of perspectives, the potential for continued employment post diagnosis for a person with dementia, and the nature of support that would enable/enables people with dementia or mild cognitive impairment (MCI) to retain employment.

## **Phase 2 – Key informant interviews**

Sixteen key informant interviews were carried out in order to help to shape and inform the development of the case studies. Key informant interviews are defined as conversations with people who are deemed to have a level of expertise in the topic of interest. Key informants were chosen from a range of backgrounds to include expertise on dementia, employment issues, government policy, and support organisations.

## **Phase 3 – Case studies**

Seventeen case studies were carried out in the final phase of the research. Each case study focused on a person with dementia who was still employed or had been employed in the previous 18 months and involved interviews with the person with dementia, a family member and a workplace representative. Data collection involved one to one interviews with the person with dementia or MCI, family members, a representative from the workplace, and other people identified by the person with dementia. Interviews used visual prompts to help the discussion.



# Findings

1. Six research papers were included in the literature review, of which only two had a specific focus on the employment of people with dementia.
2. No previous research has identified the potential for continued employment post diagnosis, thus little is known about the nature of the supports required to enable a person with dementia to continue employment post diagnosis.
3. The key informants from a healthcare background had more awareness of the issues surrounding dementia in the workplace than those from an employment background.
4. Supporting dementia in the workplace may be possible; however, each person with dementia will require different levels of support depending on the individual complexities of their situation.
5. There are a range of supports available to support people with disabilities continue or enter the labour market which could be adapted for use with people with dementia, however, to do this dementia must be conceptualised as a disability.
6. While there were many similarities in situations, each case study revealed a different experience of employment post diagnosis of dementia.
7. Continued employment post diagnosis of dementia is possible, but can be complex to manage and dependent on a number of factors.
8. The participants who continued employment felt there were many benefits of continued employment. These included helping them to manage their symptoms, keeping connected, financial security and improved overall wellbeing.
9. For some participants, continued employment was not possible, and for others the stress of continuing employment had a negative effect on their wellbeing. In these cases, the participants felt poorly supported for leaving work and adjusting to retirement.
10. Employers and colleagues need support in order to support a person with dementia in the workplace. This support may include dementia awareness training, accessible information and practical guidance.

# Conclusion

Overall, the dementia in the workplace study has identified that continued employment post diagnosis of dementia is possible, although could be complex to support. The supports required to continue working will depend on the type of job a person does, the insight they have into their symptoms and the culture of the organisation they work in as to whether they have the resources to support them. This project has highlighted the potential impact employment issues have on the lives of people with dementia, their families and their employers. This study was the first to fully explore the experiences of people with dementia in employment and has laid the foundations to shape policy and develop future research to benefit the lives of people with dementia and their families.

## Recommendations

1. An enhanced dissemination strategy for this research is required in order to raise awareness of the issues surrounding dementia in the workplace to the general public and in particular with employers.
2. Resources for employers, employees and other key stakeholders need to be developed which provide accessible information on relevant employment law.
3. Practitioners who work with individuals from the first point of contact through to post diagnosis of dementia need to consider the implications for employment and the potential financial and social impacts on the individual.
4. The post diagnostic framework needs a review of the implications of employment issues for individuals with dementia, in particular work with national work and pension agencies to ensure timely access to appropriate benefits, pensions and supports.
5. Further research is required to fully understand the problems relating to the employment of people with dementia. In particular, research is required to:
  - a. Strengthen the evidence for workplace supports identified in this study,
  - b. Further investigate the potential impact employment has on the lives of people with dementia, with a focus on potential gender differences
  - c. Understand how an employee can be managed over time in the workplace as their dementia progresses.
6. Reflecting on the recent changes in the employment of older people and the changes in state pension ages across Europe, we urgently need a stronger understanding of the international landscape for employment of people with dementia.

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