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Employer Responses to Dementia in the Workplace A Report to the Carnegie Trust for the Universities of Scotland

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Employer Responses to Dementia in the Workplace in Scotland

A Report to the Carnegie Trust for the Universities of Scotland

20 March 2018



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Executive Summary

Introduction

The reported study investigated how Scottish-based employers from different sectors respond to staff with dementia. Dementia is, and will increasingly be, a workplace issue as populations' age, working lives extend and there is better recognition of early onset dementias and earlier diagnoses. To date, however, there is a little research on the workplace experiences of people with dementia and the policies, practices and attitudes of their employers.

The requirement to support employees with dementia in the workplace has, amongst other things, a solid legal and human rights foundation. Dementia may be considered a disability under the Equality Act 2010 requiring employers to therefore make 'reasonable adjustments'. The United Nations Convention on the Rights of Persons with Disabilities 2006, in turn, reinforces this.

Using mixed-methods to interrogate workplace policies, practices and attitudes towards employees with dementia the study sought to:

- discover the extent to which employers are currently meeting their legal, equality and human rights duties;
- identify examples of good practice; and
- make recommendations for possible adaptations so that legal and human rights standards can be met.

The interdisciplinary research team was led by Professor Jill Stavert of the Centre for Mental Health and Capacity Law at Edinburgh Napier University as Principal Investigator. The team comprised of researchers from Edinburgh Napier University, the University of the West of Scotland and Heriot-Watt University. The Carnegie Trust for the Universities of Scotland funded the study.

Research Methods

This project involved three stages to the empirical data collection.

Semi-structured interviews were conducted with 20 'experts in the field'

The purpose of the expert interviews was to gauge views on the experiences of people with dementia in the workplace, the difficulties they might encounter and employer policy and practice.

An online survey was sent to employers across Scotland

The survey was directed to Human Resources (HR) departments (or equivalents). The survey gathered information on policies in place that address dementia and linked issues such as employee health and wellbeing, disability, and age management. Questions were asked about understandings of Equality Act 2010 duties and United Nations Convention on the Rights of Persons with Disabilities standards in relation to employees with dementia. There were 331 valid responses for analysis.

Semi-structured interviews were conducted with 30 employers

These interviews explored in detail employer approaches to dementia and the Equality Act 2010 'reasonable adjustment' duty and awareness of relevant UN Convention on the Rights of Persons with Disabilities rights. Participants included managers, directors and owners of small businesses as well as nurses responsible for dementia development and training.

Findings from the Expert Interviews

Fifteen of the experts agreed that dementia in the workplace was a concern now, or would be in the future. However, some interviewed believed that there was mixed employer awareness of dementia either in relation to the symptoms of dementia or acknowledgment that dementia could be a condition affecting their workforce. Only eight of the experts cited direct experience of dementia in the workplace. This may be attributed to diagnosis of dementia tending to occur after people have left work.

Three experts highlighted that persons with dementia might not consider themselves disabled and other experts questioned whether employers would see dementia as a disability falling within the protection of the Equality Act 2010. Employers would not therefore necessarily consider making the adjustments to accommodate employees with dementia. Several experts also highlighted that there could be knee-jerk assumptions made about the capabilities of people with dementia.

Three experts stated that it was harder to support an individual without a diagnosis because of the lack of clarity regarding why the individual was not able to complete or had difficulty in completing workplace tasks. Support could often only be accessed, or was only offered, once a person had received a diagnosis; with such a diagnosis also offering a level of protection under the Equality Act 2010 to employees.

Nine experts felt that the current legislation ensured that employees with dementia would be adequately supported in the workplace but that it was not necessarily put into practice. In terms of employer policy, twelve experts felt that there should be specific policies to help support people with dementia in the workplace, which might include supporting employees with dementia under a general disability policy rather than a standalone dementia policy.

Findings from the Employer Survey

Drawn from a representative sample of Scottish workplaces, this survey was completed by a core of about 165-170 workplaces. It can be assumed that those with a particular interest were more likely to have undertaken answering the survey and thus be most knowledgeable and understanding of the issues, challenges and support already available.

The responses revealed, however, that there was often a lack of awareness regarding dementia in the workplace but it does appear that symptoms and issues related to dementia in general were better understood by many. This may well be due to experiences and caring responsibilities outside the workplace where those responding may have been exposed to family members with dementia in their everyday lives. To the extent that this is generalisable to the management and workforce as a whole, the forms of support and delivery of information, intelligence and advice would benefit from recognising this revealed resource. Workplaces and colleagues alike undoubtedly have brought their opinions and understanding about dementia, and its impacts based on these non-workplace experiences, to the survey responses. Incorporating the implications of this into how advice and support is presented and offered will therefore be important in addressing and managing employer responses to dementia in the workplace.

Findings from the Employer Interviews

Only four employers stated that they had had experience of dementia in their paid or volunteer workforce. Most employers interviewed therefore had no direct experience of employees with dementia in the workplace. However, some did acknowledge that this did not necessarily mean there was not or had never been someone with dementia in their organisation.

Three employers argued that supporting someone with dementia would need to be done on a case-by-case basis, and seven employers said that the support provided would depend on the type of dementia that the employee was living with. However, several employers expressed uncertainty about how they would support someone with dementia because of lack of awareness and experience of the condition.

There was a lot of hesitation about whether dementia fell within the protection of the Equality Act 2010. However, when employers were prompted by being asked specifically whether they would see dementia as a disability, there was more certainty. Fourteen employers thought that dementia was a disability. Eleven employers were unsure about dementia being regarded as a disability. Employers believed generally that they would make reasonable adjustments to support an employee with dementia. Fifteen employers stated that they would support and individual who did not have a diagnosis.

Twenty employers stated that their organisation had all-encompassing policies or strategies already in place which would help support someone with dementia to remain in work. Most believed their general health and well-being policies were broad and needed to support many different kinds of illnesses, conditions, and disabilities and most employers did not think a specific dementia policy was required.

Conclusions and Recommendations

Every workplace will have unique experiences of employees with dementia. This study indicated that across Scotland a number of broad and important conclusions can be made upon which certain recommendations can be made.

It is clear from persons interviewed on behalf of employers that their own experience meant that in many cases they had a high degree of knowledge of the symptoms and issues associated with living with dementia. However, such knowledge appears have clearly not been gathered from experiences in or applied to workplace situations in terms of managing and supporting employees with a diagnosis of dementia or identifying those employees without a diagnosis but possibly displaying signs and symptoms of dementia. Employers expressed uncertainty about how they would support someone with dementia because of lack of awareness and experience of the condition. The real continuing potential of employees in the workplace, particularly where appropriate support is provided, is not generally recognised.

There are many examples of employers having experience of supporting workers with other physical and mental health conditions and it was understood that existing policies and procedures relating to these could be adapted for persons with dementia. However, it is clear that supporting an employee with dementia needs to be done on a case-by-case basis given the very individualised nature of a diagnosis of dementia and the way in which dementia develops in each person.

The type of support provided would therefore very much depend on the role, the progression of the condition and the nature of any impairments attributable to the dementia. Employers considered that dementia might impact on employment including attention to detail and accuracy, cognitive, memory and communication impairments, difficulties coping with an unstructured routine, the pressures of the job, the emotional impact of the dementia and use of technology.

Despite employers appearing to recognise in principle that dementia is a disability falling within the scope of the Equality Act 2010, their knowledge of the protection potentially provided to workers with dementia under such legislation, and therefore their legal responsibilities as employers, is low. In particular, there is uncertainty about the stage at which dementia would,

or should, be seen as a disability under the Equality Act and the precise nature of reasonable adjustments that are required.

Employer knowledge of relevant aspects relating to the requirement for support for the exercise of legal capacity and reasonable accommodation in the workplace, of the United Nations Convention on the Rights of Persons with Disabilities, was virtually non-existent. It is vital that this lack of knowledge of the requirements of relevant law and human rights standards is addressed from the perspective of employers, employees with dementia and those who are dependent on such employees such as family members and co-workers. In particular, it is noted that whilst diagnosis appears to be pivotal in terms of securing Equality Act 2010 protection this is not necessarily a requirement of the United Nations Convention on the Rights of Persons with Disabilities and the importance and influence of this treaty in Scotland is highlighted in this report.

Employers have expressed a desire for information and guidance on how to identify the key signs and symptoms of dementia in order to enhance their support and management of employees with dementia which would add to, or complement, existing core HR, health and well-being policies and procedures.

Recommendations

Recommendation 1: There is a need for increased employer awareness that dementia is a disability and that they therefore have legal and human rights obligations to support employees with dementia.

Recommendation 2: There must be clear guidance and training on the legal and human rights position of employers and employees in relation to dementia in the workplace.

Recommendation 3: There must be clear pathways in workplaces to enable employers to support employees with dementia, or with potential symptoms of dementia, that allows such employees to either continue in employment or to leave it in a dignified manner that fully respects their legal and human rights.

Recommendation 4: In order to effectively implement such pathways there is an urgent need for an integrated approach with management, the employee concerned, Occupational Health, vocational rehabilitation and all others involved in the implementation of the pathways.

Recommendation 5: There is a need for awareness raising amongst health care professionals to consider the implications for employment where a person is diagnosed with dementia.

Chapter 1: Introduction

- 1.1. The reported study investigated how Scottish-based employers from different sectors respond to staff with dementia. Using mixed-methods to interrogate workplace policies, practices and attitudes towards employees with dementia the study sought to:
 - discover the extent to which employers are currently meeting their legal, equality and human rights duties;
 - identify examples of good practice; and
 - make recommendations for possible adaptations so that legal and human rights standards can be met.
- 1.2. The interdisciplinary research team, led by Professor Jill Stavert of the Centre for Mental Health and Capacity Law at Edinburgh Napier University as Principal Investigator, comprised of researchers from Edinburgh Napier University, the University of the West of Scotland and Heriot-Watt University. The study was funded by the Carnegie Trust for the Universities of Scotland.
- 1.3. ‘Dementia’ is caused by illnesses such as Alzheimer’s disease, vascular dementia and Lewy body dementia. Symptoms include memory loss, difficulties with thinking and problem-solving associated with impaired cognition and sensory changes (Alzheimer Scotland 2013). Dementia symptoms and the pace of decline are both influenced by the underlying disease processes, but how these are experienced by an individual are also influenced by other factors including features of their living environment, and for employees, their work environment.
- 1.4. Dementia is, and will increasingly be, a workplace issue. Across the United Kingdom (UK) over 800,000 people currently have dementia and this number is forecast to increase by 40 per cent over the next 12 years and by 156 per cent over the next 38 years (Prince et al. 2014). At the moment, in excess of 40,000 persons living with dementia in the UK are aged under 65 years of age (Alzheimer’s Society 2017; Prince et al. 2014). In Scotland, of the estimated 90,000 people living with dementia in 2017 3,200 were under 65 years (Alzheimer Scotland 2017).
- 1.5. It can be inferred therefore, that a significant number of individuals below state pension age may be experiencing symptoms of dementia whilst in employment. Moreover, the destabilisation of retirement through extended working lives (Phillipson 2013) is likely to compound this. The UK government has sought to encourage the extension of working lives through the removal of the Default Retirement Age, raising the state pension age, and awareness raising with employers about the benefits of employing older workers (Altmann 2015; Department of Work and Pensions 2014, 2017a, 2017b;

HM Government 2011). Increasing attention on cognitive impairment, better recognition of early onset dementias and earlier diagnoses are also part of this evolving picture (Robertson et al. 2015). This myriad of factors makes it increasingly likely that employers will have to be prepared to support employees with dementia.

- 1.6. The requirement to support employees with dementia in the workplace has, amongst other things, a solid legal and human rights foundation. Dementia may be considered to be a disability under the Equality Act 2010 which potentially provides a framework for individuals to request that their employer make reasonable adjustments to support their continued employment (section 39(5) Equality Act 2010). This is, in turn, reinforced by recent developments in international human rights law. The United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD) emphasises that persons with disabilities must be genuinely able to enjoy human rights on an equal basis with others (and not have these limited or denied simply by reason of their inherent status as a disabled person) including in the workplace where reasonable accommodation must, where necessary, be provided (Article 27 CRPD).
- 1.7. Whilst it has been noted that the concept of reasonable accommodation identified in the CRPD excludes adjustments that are “*disproportionate*” and impose an “*undue burden*” (Article 2 CRPD) and has been criticised for only being applicable for people who require relatively minor adjustments (Kayess & French 2008, p. 27), it may be argued that adjustments to enable retention of persons with dementia in the workplace are not excessively burdensome. Moreover, it may be recognised that the ability to exercise one’s legal capacity is fundamental to asserting one’s rights and ensuring they are given effect. Article 12 CRPD requires that states take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- 1.8. The increasing influence of the CRPD, the fact that the UK has an obligation under international law to comply with it, and the Scottish Government’s pledge to give effect to CRPD rights (Scottish Government 2016) provides another opportunity for persons with dementia to claim their right to work in an accessible environment. Certainly, at governmental level there is an emphasis being placed on a ‘fair’ work agenda, as well as the importance of supporting people with disabilities to remain in the workplace (Fair Work Convention 2016; Scottish Government 2016).
- 1.9. However, at present, the extent to which this is being addressed by employers is unclear. To date, there has been little research on experiences of dementia in the workplace and, indeed, such that exists suggests a lack of employer support for workers with dementia (Ritchie et al. 2017). Research conducted by the University of the West of Scotland in collaboration with the Heriot-Watt University (the *Dementia in the*

Workplace: the potential for continued employment post diagnosis project, funded by the Alzheimer's Society) is one of the few studies which has explored the employment related experiences of people with dementia. This study found that continued employment post-diagnosis of dementia is possible, but this can be complex to manage and is dependent on a number of factors, including having a dementia aware supportive employer (Ritchie et al. 2017; Tolson et al. 2016).

1.10. The research reported upon here builds on this previous research. It sought to answer the following questions:

- Do employers in Scotland consider dementia in the workplace as an issue that affects their organisations, now or in the future?
- Do employers in Scotland have policies in place to support people with dementia in the workplace?
- At which point do employers in Scotland consider people with dementia to be disabled and fall within the protection of the Equality Act 2010?
- What do employers in Scotland see as 'reasonable adjustments' in relation to people with dementia with a view to making recommendations on how individuals can be supported in employment
- What is the employer position in Scotland towards individuals who may experience dementia symptoms but have not received a medical diagnosis?
- Does current legislation ensure that employees with dementia are adequately supported in the workplace?

1.11. The remainder of this report is structured as follows:

- Chapter 2 considers the existing international research base relating to the attitudes, policies and practices of employers towards older workers and what this tells us about living with dementia, and awareness and experiences of dementia, in the workplace.
- Chapter 3 discusses the methods of data collection employed in this project.
- Chapter 4 presents the information gathered from interviews with experts in the field.
- Chapters 5 and 6 presents the findings from data collected from employers across the sectors in Scotland.
- Chapter 7 presents conclusions and recommendations.

Chapter 2: Dementia in the Workplace – The Evidence Base

2.1. While dementia is, and will increasingly be, a workplace issue there has been, to date, little research on the workplace experiences of people with dementia and the attitudes, policies and practices of their employers. This chapter provides a brief overview of this, albeit small, research base outlining what it tells us about awareness of dementia as a workplace issue, the impact of dementia symptoms on work, coping strategies used by people with dementia in the workplace, responses of employers and colleagues and leaving paid employment.

Awareness of dementia as a workplace issue

2.2. Awareness that dementia in the workplace is an issue that employers need to consider is gaining currency. For example, organisations in the UK such as the Alzheimer’s Society (2015) and Age Scotland (2016a) have produced guides for employers to help them support employees with dementia. Age Scotland also delivers dementia awareness training to workplaces (Age Scotland 2016b). There are also international examples of organisations producing advice for employers (Alzheimer’s and Dementia Alliance of Wisconsin 2009; Alzheimer’s Australia 2017; Alzheimer Society of Ontario 2017).

2.3. However, the existing evidence base suggests that beyond efforts by organisations such as the Alzheimer’s Society, Alzheimer Scotland and Age Scotland, awareness about dementia generally is poor. Certainly, research exploring dementia literacy (the *‘knowledge and beliefs regarding dementia that aid recognition, management, or prevention’* (Low & Anstey 2009, p. 43)) points to a lack of knowledge surrounding the causes, risk factors and prevention, diagnosis, the different types, treatment and effects of dementia (see for example Cahill et al. 2015; Devlin et al. 2007; Friedman et al. 2015; Kim et al. 2015; Low & Anstey 2009; Lüdecke et al. 2016). Moreover, there is an extensive research base highlighting the stereotyping, stigmatising and infantilising views of people with dementia held by the general public, clinicians and even organizations advocating for people with dementia which can have negative implications in terms of quality of life (Burgener et al. 2015; Corner & Bond 2004; Devlin et al. 2007; Gove et al. 2016; McParland et al. 2012; Milne 2010; Swaffer 2014). This arguably contributes to the negative perceptions about the capabilities of people with dementia to continue in paid employment.

2.4. In some, but not all, policy narratives surrounding dementia, stereotyped views about the capabilities of people with dementia are equally prevalent. They view persons with dementia as dependent (Nedlund & Nordh 2015, p. 130) and infer, therefore, that limiting rather than enhancing their lives is justified (Baldwin 2008). The lack of awareness of dementia as being a potential workplace issue is also in part due to the

research focus in the dementia studies, gerontological and associated literatures. Research in these disciplinary areas has tended not to focus on the experiences of dementia in those aged under 65 years (Brown & Roach 2010; Clemerson et al. 2013). There is a small and developing research base around the workplace experiences of people with dementia (Chaplin & Davidson 2014; Ohman et al. 2001; Ritchie et al. 2017; Roach & Drummond 2014). The themes identified in this literature are explored in the remainder of this chapter.

Impact of dementia symptoms on work

- 2.5. The available literature which explores the experiences of people who develop dementia whilst still in employment highlights that for the majority of people the symptoms of dementia are often first noticed in the workplace (Chaplin & Davidson 2016; Ohman et al. 2001; Ritchie et al. 2015; Ritchie et al. 2017). These changes are often subtle ones that evolve over time. For example, a person may become more forgetful or slower in completing tasks (Evans 2016). The problems experienced at work, and the severity of the impact of these, depend on a number of factors including type of employment, and the individual's ability to recognise their problems in the workplace (Evans 2016; Ritchie et al. 2017).
- 2.6. For many younger people with dementia, the process of getting a diagnosis can be prolonged. For some it will take over a year, and in some cases a number of years, for a diagnosis (Hayo 2015). The consequences of this for an individual's employment can be severe, and the evidence base suggests that people may leave work before diagnosis or experience high levels of workplace stress trying to maintain their performance and productivity (Ritchie et al. 2017). Furthermore, if an individual leaves work before their diagnosis, it is unlikely that they will return to paid employment (Ohman et al. 2001; Ritchie et al. 2017). There are also issues around maintaining dignity and reputation for people with dementia. Recent research by Evans (2016) has, for example, highlighted that as performance deteriorates and tasks become more difficult, an individual can be perceived as a 'poor worker'. This further emphasises the negative stereotype of dementia and can put individuals at risk of poor treatment, workplace bullying and have negative affects on their mental health and wellbeing (Evans 2016).
- 2.7. Recent research by Ritchie et al. (2017) explored the potential for people with dementia to continue employment. Although for many the impact of dementia on work is negative, this research found evidence that with appropriate and timely support people with dementia can continue employment post-diagnosis. Aside from the obvious financial benefits of continuing employment the research suggested that it may benefit the health and wellbeing of people diagnosed with dementia if they are appropriately supported. Many participants reported the routine of work helped them to manage

their symptoms, and they felt more socially connected than those who had left employment (Ritchie et al. 2017).

Coping strategies used by people with dementia in the workplace

- 2.8. There are a number of different coping strategies discussed in the literature which have been used by people with dementia in employment, both pre- and post-diagnosis. These include flexible working, use of memory aids such as electronic calendars and diaries, and a workplace buddy system (Robertson & Evans 2015).
- 2.9. However, there is no clear consensus on the coping strategies or adjustments that will successfully support an employee with dementia. The success of coping strategies to aid continued employment post-diagnosis is dependent on the activities the individual is required to carry out, the abilities they have retained, and support from families, co-workers and management to enable employees with dementia to effectively use them to carry out their roles (Ritchie et al. 2017). Therefore, any reasonable adjustment made to their job roles needs to be considered on a person-centred basis which realises the abilities of the individual and the fit of these abilities with the job description.

Responses of employers and colleagues

- 2.10. As noted above, the co-operation and support of co-workers and employers is important for the continued employment of people with dementia. Only two studies have explicitly explored the views of colleagues and employers in relation to working with a person who develops dementia in the workplace (Ohman et al. 2001; Ritchie et al. 2017). In the study undertaken by Ritchie et al. (2017), no employers had previous experience or knowledge of dementia in employment, and many were shocked to discover that their employee had been diagnosed with dementia. Many employers considered that they did the best they could with regards to their treatment of an employee with dementia, a view which was often contested by the employee and their families (Ritchie et al. 2017). Additionally, there is an emotional impact on colleagues to consider. The worry that this might happen to them, as well as negative reactions to their friend and colleague being mistreated, can result in them questioning their own health and the integrity of their employers (Ritchie et al. 2017).
- 2.11. Workplace dementia awareness training has been shown to be successful in supporting co-workers and managers to understand the difficulties their colleague is having and to plan appropriate adjustments and support (Ritchie et al. 2017). While there have been improvements in the awareness of dementia in the workplace in recent years, the research has shown that employers generally give little attention to dementia until they are faced with an employee with a diagnosis. Initiatives in the UK such as Dementia

Friends (Alzheimer Scotland, Alzheimer's Society) and Age Scotland's Dementia and the Workplace awareness training have begun to address this gap. Similarly, trade unions (STUC 2016), occupational health (Mason 2008) and vocational rehabilitation (McCulloch et al. 2016) all have contributions to make to raising awareness of dementia in the workplace, and supporting those organisations and individuals affected to enable appropriate responses to those being diagnosed with dementia in the workplace.

Leaving paid employment

- 2.12. The academic literature draws attention to the difficult experiences people with dementia may have when leaving paid employment (Chaplin & Davidson 2016; Ohman et al. 2001; Ritchie et al. 2015, 2017; Roach & Drummond 2014; Tolson et al. 2016). Many people with dementia leave work after receiving a diagnosis, although they may have been on sick leave prior to this (Ritchie et al. 2017; Tolson et al. 2016). Continued employment or redeployment may not be considered as a serious option by employers; and communication from employers prior to work exit can be poor (Ritchie et al. 2017; Tolson et al. 2016).
- 2.13. The sense of self can be challenged if a person with dementia is forced to leave employment (Harris & Keady 2009; Ohman et al. 2001; Roach & Drummond 2014). Generally, work has a key role in an individual's personhood, biography and sense of self, which can be fractured when, for example, people retire (Barnes & Parry 2004; Price 2000). The workplace may also be very important in people's social networks, with the social isolation experienced by people with dementia once they have left work highlighted in research (Ritchie et al. 2017).
- 2.14. There may be serious financial implications for those who are forced to leave work. There may be increased financial pressures experienced by families, especially spouses who may become the sole income provider, paying mortgages and supporting dependents (Ritchie et al. 2017; Roach et al. 2016). Those leaving work may find it difficult to claim state benefits, especially those who were forced to leave work prior to receiving a diagnosis (Ritchie et al., 2017; Roach et al. 2016; Tolson et al. 2016).
- 2.15. However, it should be acknowledged that continued employment is not an appropriate option for all as work may negatively affect their wellbeing because of stress around job performance (Ritchie et al. 2017; Tolson et al. 2016). However, 'knee jerk' assumptions should not be made about the capabilities of people with dementia. The volunteering roles undertaken by some people with dementia draws attention to the societal contributions that can be made following a diagnosis. The Scottish Dementia Working

Group, a campaigning and awareness-raising group whose members all have a diagnosis of dementia, is a good example.¹

Summary

- 2.16. Awareness that dementia in the workplace is an issue that employers need to consider, is gaining currency. However, the evidence base suggests that beyond efforts by organisations such as the Alzheimer's Society and Age Scotland awareness about dementia is generally poor. There is an extensive research base highlighting the stereotyping, stigmatising and infantilising views of people with dementia.
- 2.17. The available literature which explores the experiences of those who develop dementia whilst still in employment highlights that, for the majority of people, the symptoms of dementia are often first noticed in the workplace. 'Knee jerk' assumptions may be made about the capabilities of people with dementia. There are issues around maintaining dignity and reputation for people with dementia, as they can be at risk of poor treatment, workplace bullying and suffer negative affects on their mental health and wellbeing.
- 2.18. Continued employment or redeployment may not be considered as a serious option by employers. The literature draws attention to the difficult experiences people with dementia may have when leaving paid employment. The sense of self can be challenged if a person with dementia is forced to leave employment.
- 2.19. Although for many the impact of dementia on work is negative, providing appropriate and timely support for people with dementia means that they can continue employment post-diagnosis. That being said, there is no clear consensus on the coping strategies or adjustments that will successfully support an employee with dementia and it should be acknowledged that continued employment is not an appropriate option for all.

¹ See for more details: www.alzscot.org/campaigning/scottish_dementia_working_group

Chapter 3: Research Methods

- 3.1. This project involved three stages to the empirical data collection: expert interviews, an online employer survey and employer interviews. Recruitment, data collection and data analysis for these three research stages took place between March and December 2017.
- 3.2. A Research Advisory Group was established at the start of the project consisting of nine persons from organisations with experience of working with people with physical and mental health issues in public health and social care settings, third sector organisations working with persons with dementia; organisations representing HR professionals, monitoring bodies, and one person with lived experience of dementia. The advisory group met three times during the course of the project and was invited to comment on design of the project research tools and analysis of the data collected.

Expert interviews

- 3.3. Semi-structured interviews were conducted with 20 'experts in the field'. These included health care practitioners and clinicians (n=6); lawyers (n=2), HR professionals (n=2); government policy officers (n=1); organisations supporting people with dementia (n=3); and representatives of relevant bodies which had experience of, and expertise in, workplace law, policy and/or practices which may impact on persons with dementia (n=6). In recruiting expert interview participants, the team drew on their existing links, and those of the Research Advisory Group, as well as using 'snowballing techniques' whereby interviewees were asked to suggest other potential participants.
- 3.4. The purpose of the expert interviews was to gauge expert views on the experiences of people with dementia in the workplace, the difficulties they might encounter and employer policy and practice. The interviews were used by the research team to refine views on priority areas as well as adding to the team's knowledge of the policy context so that appropriate policy recommendations could be made. The interview questions can be found in Appendix 1
- 3.5. The interviews were conducted face-to-face and were audio-recorded with the permission of the participants. Informed consent was taken. All interviews were transcribed, and thematic analysis was applied, with the assistance of NVivo software, to identify key themes in the data.

Online survey

- 3.6. An online survey was sent to employers across Scotland. The online survey tool used was SurveyMonkey. The survey was directed to HR departments (or equivalents). The survey gathered information on policies in place that address dementia and linked issues such as employee health and wellbeing, disability, and age management. Questions were asked about understandings of Equality Act 2010 duties in relation to employees with dementia. The online survey questionnaire can be found in Appendix 2.
- 3.7. The aim was to achieve a sample that encompassed a range of sectors, industries, and organisational size as well as employers from different urban and rural parts of Scotland. In identifying individual employers to contact, the research team focused distribution of the online survey to 15 local authority areas² to ensure geographical spread of responses. In order to identify individual employers to distribute the survey to, the FAME database, which contains comprehensive information on companies in the UK and Ireland, was mined. Business Directories available for the local authority areas were also mined. It should be noted that the team closely reviewed the local authority areas where responses to the survey were coming from to mitigate any geographical bias. There was also some less geographically targeted recruitment. In some cases, Business Directories only available at the Scotland level were also used to identify employers.
- 3.8. In total 4600 emails with the survey link were sent directly to employers in Scotland. In addition, a range of organisations representing employers in Scotland were asked to distribute the survey to their members. The survey link was also distributed using Twitter.
- 3.9. There were 526 responses to the survey. Of these, 195 respondents did not agree to take part in the survey leaving 331 valid responses for analysis. The online survey data were used to produce descriptive statistics, and statistical analysis was conducted using SPSS Statistics 25.

Employer interviews

- 3.10. Semi-structured interviews were conducted with 30 employers to explore in detail employer approaches to dementia and the Equality Act 2010 'reasonable adjustment'

² Aberdeen City, Aberdeenshire, Angus, Argyll and Bute, Clackmannanshire, Dumfriesshire, East Ayrshire, City of Edinburgh, Fife, Glasgow City, Highland, North Ayrshire, North Lanarkshire, South Ayrshire, and South Lanarkshire

duty and awareness of relevant UN Convention on the Rights of Persons with Disabilities rights. The interview schedule can be found in Appendix 3.

- 3.11. A multipronged approach to the recruitment of interviewees was taken (Table 3.1. presents the sectors represented in the employer interviews). Employers participating in the online survey were asked to indicate if they were happy to take part in follow up interviews. The team also drew on existing links with employers and employer organisations.

Table 3.1: Sectors represented in the employer interviews

<i>Sector (As per the Standard Industrial Classification (SIC) 2007)</i>	Number of participating employers
Agriculture, Forestry and Fishing	2
Manufacturing	1
Construction	1
Wholesale and retail trade; repair of motor vehicles and motorcycles	1
Accommodation and food service activities	2
Financial and insurance activities	2
Professional, scientific and technical activities	4
Administrative and support service activities	1
Public administration and defence; compulsory social security	5
Education	2
Human health and social work activities	9
Total	30

- 3.12. The majority of participants had HR experience and included HR heads and managers, chief officers, business partners and advisers. Participants also included managers, directors and owners of small businesses as well as nurses responsible for dementia development and training.

- 3.13. The majority of employers reported having a mixed age range of employees, typically ranging from between 18 to 65 years of age, but some did have employees (or volunteers) in their late 60s and early 70s. Numbers of employees ranged from less than five (small family run businesses and third sector organisations) to over 5,000 (large UK wide and global businesses) with some having a mix of both paid and volunteer staff.
- 3.14. The interviews were conducted face-to-face and via telephone. The interviews were audio recorded with the permission of the participants. Informed consent was taken. All interviews were transcribed and thematic analysis was applied, with the assistance of NVivo software, to identify key themes in the data.

Research integrity

- 3.15. The research received ethical approval from Edinburgh Napier Business School Research Integrity Committee (ref ENBS/2016-17/007).

Chapter 4: Expert Interviews

- 4.1. In this chapter, the findings from the expert interviews are presented. Interviews were conducted with 20 'experts in the field'. These included health care practitioners and clinicians; lawyers, HR professionals; government policy officers; organisations supporting people with dementia; and representatives of relevant bodies which had experience of, and expertise in, workplace law, policy and/or practices.
- 4.2. The first section of this chapter presents findings related to whether the experts felt that dementia in the workplace was a concern now, or would be in the future. The second section presents experts views of the support offered to employees with dementia in the workplace. The third section discusses the importance of disclosing a diagnosis. The chapter ends with consideration of future policy and legislative developments highlighted by the experts.

Is dementia a workplace issue?

- 4.3. When asked whether dementia in the workplace was a concern now, or would be in the future, 15 of the experts agreed that it was. However, some interviewed believed that there was mixed employer awareness of dementia whether this be in relation to the symptoms of dementia or acknowledgment that dementia could be a condition affecting members of their workforce. Reasons cited by experts as to why an employer might be aware of dementia included participation in dementia awareness training or if the employer was a health and social care provider. Nevertheless, it was acknowledged that many employers had little or no dementia awareness.
- 4.4. The experts themselves were asked whether they had any experience of, or contact with, people with dementia in the workplace. Only eight of the experts cited direct experience in terms of colleagues (paid workers and volunteers) or through their work as health care professionals. These limited first-hand experiences highlighted the often difficult workplace experiences of people with dementia. These are discussed later in this chapter.
- 4.5. Some of the experts discussed some of the reasons why they might not have had much contact with employees with dementia. First, the low number of individuals with early onset dementia (in other words, those of working age as currently defined) was understood to play a part as well as the stigma that might be associated with dementia meaning that some might try to hide their symptoms. It was also felt that, as dementia was often associated with older people, the needs of those with early onset dementia were often overlooked and symptoms attributed to poor performance rather than any pathological cause.

With younger people, and obviously they're the people who are most likely to be in work, if somebody's not doing well in their work, they're not performing, the last thing you would think of is dementia, and that goes for us as professionals as well (Health care practitioner/clinician)

- 4.6. Several experts suspected that a diagnosis of dementia tended to come after people have left work having been on a long-term sickness absence. Once an individual had been off work for a long period it was hard for them to return to employment.

Usually what happens is that they've already stopped working...very often people have either already given up work or are in the process of giving up work (Organisation supporting people with dementia)

Supporting employees with dementia

- 4.7. A number of the experts felt that there was a lack of employer knowledge about dementia, and how it can affect individuals. For example, some stated that employers needed to know about the different types of dementia and its symptoms.

- 4.8. Dementia was also cited by several of the experts as very different to other health conditions that employers may have encountered because of its progressive nature, as well as the variation in rates of progression. This meant that the types of conversations employers needed to have with employees with dementia were very different to other employee ill-health situations, as they were not grounded in any notions of rehabilitation.

It's unlikely that the individual will recover to their former capacity, so it's much harder I think for everybody to know how to enter into that conversation, because it isn't 'what can we do for you in the interim until hopefully things get better?' It's how do we manage the changes in your capacity, which are going to get worse over time and lead to your eventual death. That's a much harder conversation to have (Body with experience of, and expertise in, workplace law, policy and/or practices which may impact on persons with dementia)

- 4.9. In response to a question regarding the Equality Act 2010 and the UN Convention on Rights of People with Disabilities and how they relate to people with dementia in the workplace; six experts stated that they thought that dementia was a disability, thus falling within the protection of the Equality Act 2010. However, it should not be inferred that the other experts disagreed that this is the case. Three experts highlighted that persons with dementia might not consider themselves to be disabled and other experts

questioned whether employers would see dementia as a disability. A potential implication of this is that adjustments would not be made in the workplace to accommodate employees with dementia. Added to this, nine experts discussed the reactive, knee-jerk, assumptions made by employers about the capacity and capability of employees with dementia, as well as the poor employment experiences of individuals with dementia. Experts also mentioned that some health care professionals made similar assumptions about the capacity and capability of employees with dementia.

- 4.10. The expectation that people with dementia could not carry on working was countered by examples given by a few of the experts of situations where individuals had taken up voluntary, casual or seasonal work following diagnosis. Through these examples, it was demonstrated that people with dementia still had the capability to work and contribute.

[An individual] who at his diagnosis was told by the consultant that [they] should give up [their] job, who 3 months later then became a volunteer...which seemed really rather strange that somebody would be asked to give up work, and then be provided with work (Organisation supporting people with dementia)

- 4.11. The experts generally believed that there was a need for more support for employers to understand reasonable adjustments and that people with dementia may be able to continue in work. Six experts highlighted that support for employees with dementia might be 'patchy' and/or that without organisational commitment these employees would not get appropriate support.

- 4.12. It should be noted that a number of experts felt that the continued employment of a person with dementia was not always appropriate. Much depended on diagnosis, stage of diagnosis, type of dementia and the type of role the person was in. For example, continued employment might be more difficult in customer-facing, safety-critical or high-level roles. However, it did not mean that that person was not able to work.

I had a [service user who had a job that] could impact on peoples' lives. If you have somebody that works, for example, where they have large sways of data or information, or numbers that could affect or impact on their ability to be able to do their job. That is not to say the person is not able to work, it's two different things (Organisation supporting people with dementia)

- 4.13. Redeployment might enable people with dementia to remain in work. However, one expert (quoted below) highlighted that redeployment needs to be carefully managed. New roles and routines could be difficult for the person with dementia to get used to. Another expert discussed that, the dignity and self-esteem of a person with dementia needed to be taken into account, when offering redeployment options.

[People's] strengths are largely in what they're been accustomed to doing, and their roles and routine. So, to put them into something different is almost an additional challenge, not to mention how it is for any of us when we start new jobs. It's unfamiliar, it's difficult, and not always that comfortable (Health care practitioner/clinician)

The importance of disclosing a diagnosis

- 4.14. Several of the experts highlighted the important role of diagnosis in people's workplace experiences. Three experts stated that it was harder to support an individual without a diagnosis because of the lack of clarity regarding why the individual was not able to complete or had difficulty in completing workplace tasks. Support could only be accessed, or was only offered, once a person had received a diagnosis.

This is where it gets tricky, because the clinical services are based around a clinical diagnosis, and in order to access a lot of the third sector, or the partnership employment supports, you have to have a diagnosis. So, getting over this, 'oh well we don't want to distress the person by giving them a diagnosis of dementia, or the family don't want them to know' (Health care practitioner/clinician)

- 4.15. A diagnosis could offer a level of protection to employees, who might otherwise be performance-managed out of the workplace if there was no clinical explanation of why they might not be performing.

Until you have that formal diagnosis, from the employer's side, I assume the view is, well we don't know why you're not able to fulfil your role...if somebody is not fulfilling their role then that's it, they're out of a job (Health care practitioner/clinician)

- 4.16. However, a number of experts outlined that it could take a number of years before an individual was diagnosed with dementia, especially for those with early onset dementia.

- 4.17. The Equality Act 2010 is unlikely to provide security unless there is a clinical diagnosis. However, it was noted by some experts that many people do not want to disclose a diagnosis of dementia to their employer. This makes it very difficult for employers to put appropriate support in place. Many of the experts talked of the need for an open and supportive culture in workplaces with good policies and basic good practice in terms of communication and the working environment so that people felt more comfortable about disclosing a diagnosis of dementia. The authors of this report would

also add that, employers should not feel that they are under pressure to be able to diagnose dementia. Rather they should foster working environment where those who have received a medical diagnosis feel able to disclose this.

- 4.18. It was suggested by some experts that there was scope for employers to have more information about the symptoms of dementia so that they could potentially identify possible symptoms of dementia. The need for line managers to have good relationships with their employees was also considered to be important by one of the experts so that they are able to notice any changes that might be attributable to dementia and sensitively approach employees where there is concern. The authors of this report would argue that this could potentially help avoid situations of employees exhibiting symptoms of dementia being performance-managed out of the workplace.

Perhaps it's only going to come to light if perhaps there was a performance improvement process implemented for example, and that's what was the flag, that was the trigger perhaps to...but it's the reliance I suppose on declaration, but I would hope that you would know, I would hope with a line manager that I would know my people well enough to know (HR professional)

- 4.19. Another expert argued that, even where there is no diagnosis of dementia but an employee is experiencing, for example, memory problems, there should still be scope to refer them to occupational health for a risk enablement plan. This would be in line with processes relating to other situations involving ill-health.

Future policy and legislative development

- 4.20. The experts were asked whether they felt that current legislation ensured that employees with dementia are adequately supported in the workplace. Nine felt that the current legislation ensured that employees with dementia would adequately supported in the workplace but that it was not necessarily put into practice. Some of these nine experts also added the caveat that the legislation only provided adequate support to those who had a diagnosis. In this context, two experts in particular argued that the legal framework as it stands needed first to be properly understood and maximum use made of it before any law reform was considered.

The law's a great law, I'm not for changing any of it. I'm just for enacting it now thanks. So, it comes down to how we apply that legislation for any condition (Health care practitioner/clinician)

- 4.21. In terms of employer policy, 12 experts felt that employers should have their own specific policies to help support people with dementia in the workplace. This included,

the support of employees with dementia being included as part of a general disability policy. Five did not see the need for any specific policies.

- 4.22. The view was expressed by some experts was that there was a general need for well thought out HR policies. However, it was acknowledged by these experts HR policies on their own are not enough. Local awareness raising with line managers, for example, was needed; and there could also be better use of occupational health.

Summary

- 4.23. Fifteen of the experts agreed that dementia in the workplace was a concern now, or would be in the future. However, some interviewed believed that there was mixed employer awareness of dementia either in relation to the symptoms of dementia or acknowledgment that dementia could be a condition affecting members of their workforce. Only eight of the experts cited direct experience of dementia in the workplace. This may be attributed to diagnosis of dementia tending to occur after people have left work.
- 4.24. The experts sensed that there was a lack of employer knowledge about dementia and how it can affect individuals. Three experts highlighted that persons with dementia might not consider themselves to be disabled and other experts questioned whether employers would see dementia as a disability falling within the protection of the Equality Act 2010. Employers would not therefore necessarily consider making the adjustments to accommodate employees with dementia. Several also highlighted that there could be knee-jerk assumptions made about the capabilities of people with dementia.
- 4.25. Three experts stated that it was harder to support an individual without a diagnosis because of the lack of clarity regarding why the individual was not able to complete or had difficulty in completing workplace tasks. Support could often only be accessed, or was only offered, once a person had received a diagnosis; with such a diagnosis also offering a level of protection under the Equality Act 2010 to employees.
- 4.1. Nine experts felt that the current legislation ensured that employees with dementia would adequately supported in the workplace but that it was not necessarily put into practice. In terms of employer policy, twelve experts felt that there should be specific policies to help support people with dementia in the workplace, which might mean supporting employees with dementia as part of a general disability policy rather than a standalone dementia policy.

Chapter 5: Employer Survey

- 5.1. Given the focus on employers in establishing the environment and culture within the workplace, an online survey was undertaken of a representative sample of workplaces across Scotland. There were 331 valid and usable responses for analysis in this chapter.
- 5.2. The first section of this chapter describes the workplaces who responded to the survey, and this is followed by an analysis of responses. The chapter concludes with a summary of the key findings.

The survey respondents

- 5.3. The participating workplaces were asked to select their main activities from a list. As Table 5.1 shows, 2% of workplaces were in primary sectors (agriculture, fishing and forestry and the utilities), 7.5% in manufacturing and 6% in construction. This broadly reflects the employment structure of the Scottish economy. Over 45% were in private services, 32% in public services, and 7.5% in charities and similar organisations.

Table 5.1: Main Activity of the workplace

	Number	%
Agriculture, Forestry and Fishing	3	1.1
Manufacturing	21	7.5
Electricity, gas, steam and air conditioning supply	1	0.4
Water supply, sewerage, waste management and remediation activities	2	0.7
Construction	17	6.1
Wholesale and retail trade; repair of motor vehicles and motorcycles	3	1.1
Transportation and storage	5	1.8
Accommodation and food service activities	7	2.5
Information and communication	13	4.6
Financial and insurance activities	9	3.2
Professional, scientific and technical activities	23	8.2
Administrative and support service activities	23	8.2
Other private services	43	15.4

	Number	%
Public administration and defence; compulsory social security	34	12.1
Education	19	6.8
Human health and social work activities	36	12.9
Other (mostly third sector organisations)	21	7.5
Total	205	100.0

- 5.4. When asked about type of ownership sector, over half of participating workplaces identified the private sector; a quarter suggested they were social enterprises or third sector organisations; and under a fifth were in the public sector (Table 5.2). Again, this suggests there is reasonable coverage of types of workplaces in Scotland (Scottish Government, 2017).

Table 5.2: Workplace type

	Number	%
Public sector organisation (includes local authorities, councils, government departments, civil service, state schools,	44	18.7
Private sector organisation (includes partnerships, private limited companies, family-owned businesses, self-employed)	132	56.2
Third sector organisation (includes charities and not for profit organisations)	55	23.4
Social enterprise (includes profit and not for profit)	4	1.7
Total	235	100.0

- 5.5. Most workplaces (64%) were the sole premises of the business (Table 5.3), although over a third were part of a larger organisation and so perhaps could refer to others in the wider infrastructure of the business for support and information.

Table 5.3: Structure of the organisation

	Number	%
A single independent establishment	147	63.6
Part of a larger organisation	84	36.4
Total	231	100.0

- 5.6. There was a good range of workplace sizes (Table 5.4) with sufficient numbers from micro to large workplaces so that all Scottish enterprises were adequately represented. Over half (56.6%) also had staff on non-standard contracts (volunteers, temporary and casual workers, interns, etc.) in their workforce.

Table 5.4: Number of employees

	Number	%
Less than 10	53	26.2
10-49	59	29.2
50-249	41	20.3
250-999	16	7.9
1,000 or over	33	16.3
Total	202	100.0

- 5.7. Responses were received from across Scotland (Table 5.5), with cities, commuting suburbs, towns and rural and island locations included. However, because of the sampling frame used (see Chapter 3 for further details), Edinburgh, Fife and Aberdeen (Aberdeen City and Aberdeenshire) were over-represented although this should not have led to any particular biases in answers and comments in subsequent questions.

Table 5.5: Location of establishment

	No.	%		No.	%
Aberdeen City	14	5.9	Inverclyde	2	0.8
Aberdeenshire	7	2.9	Midlothian	11	4.6
Angus	2	0.8	Moray	4	1.7
Argyll and Bute	11	4.6	North Ayrshire	1	0.4
Edinburgh City	36	15.1	North Lanarkshire	5	2.1
Clackmannanshire	1	0.4	Orkney Islands	1	0.4
Dumfries and Galloway	2	0.8	Perth and Kinross	5	2.1
Dundee City	4	1.7	Renfrewshire	1	0.4
East Ayrshire	5	2.1	Scottish Borders	1	0.4
East Dunbartonshire	1	0.4	Shetland Islands	2	0.8
East Lothian	2	0.8	South Ayrshire	2	0.8

	No.	%		No.	%
East Renfrewshire	1	0.4	South Lanarkshire	13	5.5
Falkirk	2	0.8	Stirling	4	1.7
Fife	44	18.5	West Lothian	6	2.5
Glasgow City	16	6.7	Multi-location / other	14	5.9
Highland	18	7.6	Total	222	100.0

5.8. As expected, most workplaces had a spread of age groups in employment (Table 5.6). Those aged 26-49 years were the largest group employed in the participating workplaces, followed by those aged 50-59 years.

5.9. Of the workplaces who were able to provide estimates of the proportions of those aged 60-64 years and 65 years and over in their workforce (164 and 145 respectively); the majority had under 10% of their workforce in these age groups. However, for a sizeable number (about a third), two out of five of their workers were aged 60-64 years. This is the age group most likely to be affected by early onset dementia directly or through caring for a family member.

Table 5.6: Proportion of older workers in the participating workplaces

	Aged 60-64		Aged 65 and over	
	Number	%	Number	%
None	35	21.3	54	37.2
Less than 10%	65	39.6	61	42.1
10% to 20%	33	20.1	9	6.2
More than 20%	16	9.8	6	4.1
Don't know	15	9.1	15	10.3
Total	164	100.0	145	100.0

Note: 164 responses (60-64 years) and 145 responses (65 years and over)

Policies and strategies related to older workers and dementia

5.10. Very few workplaces reported having specific policies for older workers (5.7%) or for those with dementia (2.1%). Indeed, very few answered this and related questions

(Table 5.7) and even amongst those who did only 10% and under 4% respectively had explicit measures in place.

Table 5.7: Does this workplace have any specific policies or strategies:

		No.	%	Of those answering (%)
for older employees (those aged 50 plus)?				
Valid	Yes	19	5.7	10.3
	No	152	45.9	82.6
	Don't Know	13	3.9	7.1
	Total	184	55.6	100.0
Missing		147	44.4	
Total (full survey)		331	100	
regarding the rights of employees who have dementia?				
Valid	Yes	7	2.1	3.8
	No	146	44.1	79.3
	Don't Know	31	9.4	16.8
	Total	184	55.6	100.0
Missing		147	44.4	
Total (full survey)		331	100	

- 5.11. Approximately 1 in 6 respondents reported experience of dementia awareness activities in their workplace and other activities (Table 5.8), representing over a quarter of those answering this question explicitly.

Table 5.8: Are you aware if your organisation has ever undertaken any dementia awareness raising activities with staff?

		Number	%	Of those answering (%)
Valid	Yes	50	15.1	27.2
	No	112	33.8	60.9
	Don't Know	22	6.6	12.0

	Number	%	Of those answering (%)
Total	184	55.6	100.0
Missing	147	44.4	
Total (full survey)	331	100.0	

Attitudes to workers with dementia

- 5.12. A series of questions were posed to elicit attitudes towards employees with dementia. About a half of those completing the survey (167-169 out of 331) responded to each of these questions (Table 5.9).
- 5.13. Although only a quarter of respondents believed that employees with dementia were a concern to their workplace, there was a relatively significant awareness of the need to support these workers (43%). However, despite this, fewer than 1 in 11 (8.9%) responding to this question had policies already in place to support workers with dementia. Recognition of the need for such support meant that about 1 in 6 were reviewing their approach to dementia support, suggesting a further 10 workplaces were considering introducing an explicit strategy. Together these responses would mean 20% of workplaces answering this question would have a strategy to support workers with dementia across all those surveyed. However, this would represent under 7% who positively stated that measures were in, or being put in, place.
- 5.14. Only 23 of those responding had experience of workers with dementia. While all sizes of workplace were involved, 10 of these had over 1000 employees where dissemination of good practice would arguably be more easily facilitated. Apparently, there was a negligible influence of having to deal with these issues directly as just 2 of the 23 workplaces who had experiences of workers with dementia, attributed such experiences to the subsequent introduction of a specific dementia policy.

Table 5.9: Employer attitudes to workers with dementia

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total %
Employees with dementia are not considered to be a concern for this organisation	16	29	30.2	19.5	5.3	100
This organisation is increasingly aware of the need to do more to support employees that have dementia	9.5	33.3	34.5	16.1	6.5	100
This organisation already has a policy in place to support employees with dementia	2.4	6.5	23.7	48.5	18.9	100
This organisation is currently reviewing its approach with a view to developing a policy to support employees with dementia	3	12.6	38.9	30.5	15	100

5.15. Over half (53.6%) of those responding saw dementia as a disability while over a third (34.6%) did not know. About the same proportion had heard of the UN Convention on the Rights of Persons with Disabilities (53.2%). A majority of respondents (60.1%) considered employees with dementia to be protected under the Equality Act 2010. Employers have a statutory requirement to provide reasonable adjustments in accordance with the Equality Act. In Chapter 1, we argued that the UN Convention on the Rights of Persons with Disabilities has the potential to reinforce employees' rights under the Act. We will discuss the potential implications of the level of employer knowledge about this area of law and human rights indicated in the data we collected in the employer interviews (Chapter 6).

5.16. Contrasting with some of these areas of less than full knowledge, 79.6% of those answering the survey considered they had 'good' or 'very good' awareness of the symptoms of dementia. Respondents were asked to indicate their awareness of common symptoms associated with dementia. Dementia is a condition caused by different illnesses and the trajectory and presentation of these different illnesses vary. However, there are some common symptoms such as altered cognition, memory loss, communication problems and sensory changes (Alzheimer Scotland 2013). Almost all

the respondents identified that the symptoms detailed in the survey were associated with dementia; apart from 'issues with visual perception' where over a quarter were unsure or disagreed and another 10% did not know whether this was a symptom of dementia (Table 5.10).

- 5.17. This high degree of awareness of the consequences of dementia for the individual could be contrasted with the low levels of awareness in the workplace and suggests knowledge drawn from outside the work environment. This presents the opportunity, potentially, for transfer of this understanding into the workplace and employer policy and practice.

Table 5: 10: Dementia can cause...

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Total %
Memory loss	51.2	46.4	1.8	0	0	0.6	100
Difficulties in effective planning	44	50	3.6	0	0	2.4	100
Communication problems	42.8	50	4.8	1.2	0	1.2	100
Confusion over times and places	49.4	47.6	3	0	0	0	100
Issues with visual perception	27.7	36.1	21.1	4.2	0.6	10.2	100
Mood changes	46.4	46.4	6	0.6	0	0.6	100

- 5.18. Regardless of whether the particular workplace had active dementia policies and strategies, in about 70% of cases respondents tended to report positive attitudes towards changes and adaptations being offered in the workplace when dementia was revealed (Table 5.11). However, although 85% supported changes being made, there were still reservations from sizable numbers when investment in equipment, reductions or alterations in hours, increased support from colleagues, training, and other intrusions into work arrangements were suggested.
- 5.19. Consistent with the fairly positive views on what forms of support should be made available or offered to those with dementia, as described above, 84% of those responding agreed that an employee should be offered support by their employer if they show symptoms of dementia but have not yet received a diagnosis (Table 5.12).

Table 5:11: To what extent do you agree or disagree with the following statements (%)

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Total %
Employers should make 'reasonable adjustments' for employees with dementia	50.6	34.9	9.6	1.8	1.2	1.8	100
Employees with dementia should be offered a change in hours/flexible working	27.5	47.5	22.5	1.9	0.6	0	100
Employees with dementia should be offered a change in job to take on lighter or less demanding work	25	46.9	26.3	1.9	0	0	100
Employees with dementia should be offered a reduction in workload	23	44.7	29.2	3.1	0	0	100
Employees with dementia should be offered increased IT support/specialist IT equipment to support them with their work	25.8	43.4	27	3.8	0	0	100
Employees with dementia should be offered extra support from work colleagues	20.8	48.4	25.8	5	0	0	100
Employees with dementia should be offered re-training to be able to do another job	17.5	45.6	30	6.3	0.6	0	100
Employees with dementia should be offered time off to attend medical appointments	44.7	39.8	13.7	1.2	0.6	0	100
Employees with dementia should be offered counselling or mentoring support	30	50	17.5	2.5	0	0	100

Table 5:12 Should support be offered before diagnosis if symptoms of dementia are showing?

	Number	%
Strongly agree	56	34.6
Agree	80	49.4
Neither agree nor disagree	13	8.0
Disagree	6	3.7
Strongly disagree	1	0.6
Don't know	6	3.7
Total	162	100.0

- 5.20. Given the lack of knowledge, internal policies and experience of dementia in the workplace, the survey sought to identify what organisations and authorities would be approached for advice if an employee were to develop symptoms of dementia or be diagnosed with dementia. Although 15 types of agency were suggested, few of these were mentioned by more than 25 respondents. Charities or third sector organisations such as Alzheimer Scotland (identified by 95 respondents); Occupational Health (90 respondents); specialist HR consultants (41 respondents) or specialist consultants (37 respondents); various government agencies and initiatives (Healthy Working Lives, Fit for Work, etc.); and the workplace's own HR and internal advisors were identified.
- 5.21. This absence of an obvious consensus on sources of information and guidance, the range of possible bodies cited, coupled with the general lack of awareness and the apparent gaps confirms that there is a need to improve understanding, signposting and advice facilities in the area of dementia.
- 5.22. As with most of the survey, about 166 responded to detailed questions as to whether their workplace would welcome information, support or advice to improve knowledge and understanding of dementia in the workplace. Although over three-quarters (78.3%) of those responding to these questions answered positively, a substantial proportion were not in favour of such support. While there were all sizes of employer with such an opinion, it was more prevalent amongst SMEs. Information and advice required included health and safety needs assessments and awareness training; tailored and expert advice for their own situation was attractive to about a fifth of those responding. Modes of delivery were varied with some looking for (inter)active support, toolkits, leaflets, online guides and other forms of information, but about half strongly argued these should be free.

Summary

- 5.23. Drawn from a representative sample of Scottish workplaces this survey was completed by a core of about 165-170 workplaces. It can be assumed that those with a particular interest were more likely to have answered the survey and thus be most knowledgeable and understanding of the issues, challenges and support already available.
- 5.24. The responses revealed, however, that there was often a lack of awareness regarding dementia and the workplace but it does appear that symptoms and issues were better understood by many than suggested by these work-oriented questions. This may well be due to experiences and caring responsibilities outside the workplace where those responding may have been exposed to family members with dementia in their everyday lives. To the extent that this is generalisable to the management and workforce as a whole, the forms of support and delivery of information, intelligence and advice would benefit from recognising this revealed resource.
- 5.25. Workplaces and colleagues alike undoubtedly have brought their opinions and understanding about dementia, and its impacts based on these non-workplace experiences, to the survey responses and so incorporating the implications of this into how advice and support is presented and offered will be important in addressing and managing employer responses to dementia in the workplace.

Chapter 6: Employer Interviews

- 6.1. This chapter reports on the findings from the 30 employer interviews. The majority of participants had HR experience and included HR heads and managers, chief officers, business partners and advisers. Participants also included managers, directors and owners of small businesses as well as nurses responsible for dementia development and training. As detailed in Chapter 3 the employers represented a range of different sectors.
- 6.2. The chapter is structured as follows. The first section considers the employer's experiences of dementia in the workplace. The second and third sections discuss employer views regarding their ability to support someone with dementia at work, and their awareness of the Equality Act 2010. Section 4 outlines the role that employees disclosing a diagnosis of dementia to their employer in the support they receive. The final two sections examine (potential) policies to support employees with dementia, and training and dementia awareness raising.

Experience of dementia in the workplace

- 6.3. Only four employers stated that they had had experience of dementia in the workplace either in their paid or volunteer workforce. While most employers had no direct experience of employees with dementia in the workplace, some did acknowledge that this did not necessarily mean there was not or had never been someone with dementia in the workplace, and recognised that some employees may not want to disclose a diagnosis.

I've been here for almost 2 years, and to my knowledge there's not been a live example of dealing with dementia in the workplace. Though that doesn't mean that of the [over 3,500] employees that we don't have people who have dementia (HR professional)

- 6.4. Although most employers had no direct experience of dementia in the workplace, many mentioned their own personal experiences and understandings of dementia through caring for family members. Several employers also mentioned the growing number of employees who had caring responsibilities for persons with dementia.
- 6.5. As well as supporting carers at work, employers also mentioned the demographic and legislative context – in other words, the ageing population and the extension of working lives (see Chapter 1 for further details) - as reasons why they had considered/been aware of dementia in the workplace. Eleven employers mentioned taking part in awareness raising activities in their workplace regarding dementia. All employers within

the human health and social work activities sector had formal training for employees who worked with people with dementia.

- 6.6. Employers who had not considered dementia in the workplace had a predominantly younger workforce where dementia was not on their agenda. Several indicated that they would not think about it until they had direct experience of an employee with dementia.

Dementia hasn't been thought about within this organisation. It's not something which we've had to deal with and it's not something that's come up on our radar to think about. The bulk of our employees are early 20s to mid-30s (Finance director)

Supporting employees with dementia

- 6.7. Employers were asked how easy they thought it would be for their organisation to support someone with dementia at work.

- 6.8. In discussing the type of support that could be offered to an employee with dementia, eight employers stated that they would treat dementia the same as any other health condition. Although most employers had no direct experience of an employee with dementia they did have experience of other health conditions which were seen to be either similarly progressive in nature, for example multiple-sclerosis and cancer, or had similar symptoms, such as cognitive and memory impairments such as dyslexia, stroke and brain damage.

- 6.9. Three employers argued that supporting someone with dementia would need to be done on a case-by-case basis, and seven employers said that the support provided would depend on the type of dementia that the employee was living with. As such, it could be argued that employers were aware that dementia affected individuals in different ways.

One of the things that we believe, and that we focus on in the support we give, is that everybody is different. So, you take 3 people who have got Alzheimer's and look at them on 3 different days, you've probably got 20 different sets of experiences there...It might be easier than you would imagine, but it also might be a lot more difficult than you would hope (Business owner)

- 6.10. Three employers detailed that they would need to consider the job role of the individual, and three employers did not know how they could support an individual until they had had direct experience of dementia in the workplace.

- 6.11. Several employers suggested ways in which dementia might affect an employee's ability to do their job. These included attention to detail and accuracy, cognitive, memory and communication impairments, difficulties coping with an unstructured routine, the pressures of the job, the emotional impact of the dementia, and use of technology.
- 6.12. Use of technology was one of the most frequently mentioned ways in which employers suspected an employee with dementia might have difficulties at work with some employers making the assumption that having dementia meant not being able to use technology.

What I understand as dementia, is that in a way you're almost reverting back to younger days, and the way the technology and everything is now, people are saying that if you give a person with dementia a television with on and off buttons to press to change the channels, they can cope with that, but give them a remote control and they don't know what to do with it (HR professional)

- 6.13. One employer also expressed concerns about whether customers would be supportive of an employee with dementia, and about how to get across to customers the need to adapt their expectations, without labelling that person.

Because a large majority of roles here are front facing, the biggest critics we have are the people who come here, and a few of them are not very friendly to young students, trying to learn new skills. So, goodness knows what they would be like with somebody who had an illness that maybe made them a bit slower, or made them forget something, or maybe they wouldn't communicate as well as someone without dementia (Company director)

- 6.14. Other challenges to, or difficulties in, providing support for employees with dementia were also mentioned. These included that dementia was a degenerative condition (and there would come a point where adjustments could no longer be made); the extent to which an employee with dementia was aware of their own condition; the financial implications of providing additional support (particularly for small businesses, and organisations under pressure to make cost savings, and cost cuts); and the health and safety implications, for example, for employees responsible for dispensing medication or who undertook lone/remote working.
- 6.15. The majority of employers stated they would support an employee with dementia by referring them to occupational health. Employers would also request additional support from HR, seek advice from external specialists and provide information and advice about general health and well-being interventions provided for all employees: for

example, confidential contacts, mental health first-aiders, welfare officers, counselling services, and private health care provision.

The Equality Act 2010 and reasonable adjustments for employees with dementia

- 6.16. Employers were asked whether dementia fell within the protection of the Equality Act 2010. There was considerable hesitation about this but, when they were specifically asked whether they would see dementia as a disability, there was more certainty that dementia was a disability which fell within the protection of the Equality Act 2010. Fourteen employers thought that dementia was a disability.
- 6.17. Several employers referred to the definition of a disability under the Equality Act 2010 (in other words, a physical or mental impairment that has a 'substantial' and 'long-term' adverse effect on a person's ability to carry out normal daily activities (see section 6(1)(a) and (b) Equality Act 2010). Only one employer said they would also link age as a protected characteristic (section 5 Equality Act 2010).
- 6.18. Eleven employers were unsure about dementia being regarded as a disability. Several employers stated that it would depend on the impact the dementia had on the performance of a person's role as well as the impact on the individual. Employers expressed concerns about knowing, and recognising, at what point dementia would, or should, be seen as a disability.

From the point of view of the Equality Act, when does it become a disability? That's something for somebody smarter than me. It could be 5 years that they could be functioning perfectly OK, but they may well have the early stages of dementia. It's difficult to put a line in the sand for that (Company director)

- 6.19. There were many suggestions for reasonable adjustments under the Equality Act 2010. These were wide ranging and very much dependent on the nature of the business or organisation. The most frequently mentioned adjustments were changing roles and responsibilities, providing additional support (for example, training) and supervision, flexible working, re-deployment, and providing additional IT support (for example, voice recognition software and the use of task lists and reminders). Several employers emphasised the need to adopt a person-centred approach.
- 6.20. The reasonable adjustments implemented by the minority of employers who had had experience of dementia in the workplace included re-deployment, additional support, and training.

- 6.21. However, some employers were unsure about what would be the most appropriate reasonable adjustments because of a lack of awareness and understanding of dementia. The appropriateness of, or potential for, reasonable adjustments was also dependent on the nature of the workplace. Re-deployment was a consideration for some of the larger organisations (with some having a (medical) redeployment register) but for the smaller organisations it was seen as a more difficult adjustment to make, largely due to the lack of availability of a suitable, alternative, position.

We are a [small] organisation. So, we won't have the same opportunities that many employers of a different size will have. It is possible to re-deploy, but if we're fully staffed and someone has a problem, we may not be able to re-deploy them, and even if we did they may not be able to do that job either, either because of their dementia, or because of the technical requirements of that job (Chief executive)

- 6.22. Some employers stated that the emphasis is on 'reasonable' in making adjustments and therefore considered it may not be cost effective to provide an adjustment, such as adding higher levels of supervision, when another person might more easily undertake the work. As previously revealed, some employers also suspected that there may come a point where making reasonable adjustments was no longer appropriate owing to the degenerative nature of dementia.

We would do everything we could to make a reasonable adjustment, but I suppose you'd get to the point where you'd ask, 'when does it become unreasonable?', and us wanting to keep them in the workplace, are we being more of a hindrance than a help? Is it the right thing for them to transition into something different? And do we need to have that difficult conversation with them about it? (HR professional)

The importance of disclosing a diagnosis

- 6.23. Employers were asked how they would identify, and support, an employee who was showing early signs and symptoms of dementia but had not yet had a formal diagnosis. Fifteen employers stated that they would support an individual who did not have a diagnosis. Five employers felt that a lack of diagnosis made it difficult for them to provide support.

- 6.24. Several interviewed recognised that some employees may not want to disclose a diagnosis of dementia, likening it to the stigma surrounding mental health in general. Mental health was increasingly being recognised by many employers as a growing issue in the workplace and interventions were in place for this, such as mental health first aiders, management training in mental health awareness, employee assistance programmes (which include a counselling service), confidential contacts and welfare

officers, and links to the *See Me* programme (which aims to tackle mental health, stigma and discrimination in Scotland). Employers expressed hope that interventions such as these would encourage employees with dementia to seek advice and support.

That's been quite a new development here, over the last 18 months probably, that mental health's had such a big focus, but it has to, and I don't think we're the only employer who've done that, but it has to, because it has a much bigger focus in society generally (HR professional)

- 6.25. Many of the employers felt that they had a sufficiently open, positive culture (with one small business having a specific open-house policy), and close-knit teams which meant that employees would be confident about speaking to their managers.
- 6.26. Notwithstanding this, where a worker did not disclose a diagnosis of dementia, or had not yet received a diagnosis, many employers felt that the systems they had in place to support employees at work would still help to recognise if someone was experiencing difficulties. Such systems included: monthly supervisory meetings, quarterly formal meetings with employees who worked remotely, informal feedback from clients, one-to-one supervision (where well-being was discussed), and dedicated health and well-being HR advisors, who had a remit to coach and develop managers' skills regarding employee well-being and conducting difficult conversations with employees (regardless of the existence of a health issue). The majority of employers also stated that they would refer an employee to occupational health if they had concerns.
- 6.27. As mentioned previously in this report, the Equality Act 2010 does not provide security if a clinical diagnosis is not disclosed, and for some employers not having a diagnosis would make it difficult to put the right adjustments in place. However, several employers said that even if somebody had a health condition which did not fall within the Equality Act 2010 and they could make reasonable adjustments then they would do so in order to try to keep that person in the workplace. Many employers felt that it was the right thing to do.

We're always going to have the need to support more people who've just got stuff going on. They don't necessarily have a formal diagnosis of any particular disease. I don't think having a diagnosis would be the thing that would be the catalyst for putting in place reasonable adjustments (Business owner)

- 6.28. The rights related to exercise of legal capacity, and support for this, and employment identified in the CRPD have the potential to reinforce the position of persons with dementia, both under the Equality Act 2010 and otherwise, in the workplace (see Chapter 1). However, it was clear from the data gathered from both the employers'

online survey (Chapter 5) and employer interviews that knowledge of this treaty and its implications in this context is very low.

Policies to support employees with dementia

6.29. Twenty employers stated that their organisation had all-encompassing policies or strategies already in place which would help support someone with dementia to remain in work. Most believed their general health and well-being policies were broad and needed to be to support many different kinds of illnesses, conditions, and disabilities. Policies and strategies were supported by workplace interventions such as mental health awareness training for line managers, and employee assistance helplines. Most employers also did not think a specific dementia policy was required.

I wouldn't say to put a specific policy in for dementia, because there are so many different illnesses, and different things, you'd never be done with it...I wouldn't think that it would be of benefit to us to start limiting, and doing specific policies for different things (HR professional)

6.30. Only two employers stated that their organisation did not have any policies or strategies already in place which would help support someone with dementia to remain in work.

6.31. The possibility of an employee with dementia being dismissed through a loss of capability was recognised by some employers. Some of the smaller organisations either had no or only basic policies or strategies in place and so would not be able to adequately support an employee with dementia; they would therefore follow a generic capability assessment process instead. Some of the larger employers also mentioned capability assessment processes under performance procedures, although the existence of health issues would not necessarily prevent the performance procedures from being followed. That being said, some employers did recognise that looking at reporting procedures, and asking the right questions, was vital with regard to performance procedures for somebody who has, or may have, dementia.

6.32. As was apparent in the online survey of employers reported in Chapter 5, some employers indicated a lack of awareness and understanding of dementia resulting in a degree of uncertainty about whether dementia needed to be specifically mentioned in existing policies and procedures. Some stated that they would not make any adaptations until they had direct experience of an employee with dementia.

If I did think we needed a more specific policy we could certainly add that. But, that would probably be led by a situation in a way. Right now, I don't know how we would adapt what we've got, because I don't know what we'd have to do. I don't

know how we could do anything different, other than trying to make the reasonable adjustments that we would make for any other employee (HR professional)

- 6.33. Although employers generally did not think a dementia specific policy or procedure was required, they did believe that they would benefit from guidance which to help support management, for example an awareness document showing the key signs and symptoms of dementia, which would add to, or compliment, existing core policies and procedures.

Training and dementia awareness raising

- 6.34. As previously detailed, 11 employers had already taken part in dementia awareness training and awareness raising activities. When asked whether they would like to be involved in any awareness raising activities regarding dementia in their workplace, 14 employers wanted to be involved in awareness raising activities regarding dementia in the workplace in the future. Three employers expressed no interest in getting involved in awareness activities.
- 6.35. Employers acknowledged that employees were aware of dementia either through their own personal experiences, or media, television, etc. However, notwithstanding this, there was a lack of application of this knowledge to the workplace, largely due to dementia being associated with those of post-retirement age. Managers and co-workers may therefore not recognise someone who is showing the early signs and symptoms of dementia, despite having an awareness of the symptoms.
- 6.36. Several employers mentioned their interest in managing an ageing workforce and saw dementia awareness fitting into this pro-active approach, particularly if it provided pre-emptive assistance. Others saw it fitting into a wider mental health awareness training. Many employers were also interested to know whether there was support available from external organisations, such as Alzheimer Scotland or Age Scotland.
- 6.37. Employers who were not interested in awareness raising deemed that it was not relevant because of their predominantly younger workforce and also that the cost of training, in particular, was prohibitive for a small organisation though there was no indication that they had knowledge about these costs .

Summary

- 6.38. Only four employers stated that they had had experience of dementia in the workplace either in their paid or volunteer workforce. Therefore, most employers had no direct experience of employees with dementia in the workplace. Some did acknowledge that

this did not necessarily mean there was not or had never been someone with dementia in their organisation.

- 6.39. There was a lot of hesitation about whether dementia fell within the protection of the Equality Act 2010. Fourteen employers thought that dementia was a disability. Eleven employers were unsure about dementia being regarded as a disability. Several employers expressed concerns about knowing, and recognising, at what point dementia would, or should, be seen as a disability. Employers believed generally that they would make reasonable adjustments to support an employee with dementia.
- 6.40. Three employers argued that supporting someone with dementia would need to be done on a case-by-case basis, and seven employers said that the support provided would depend on the type of dementia that the employee was living with. However, several employers expressed uncertainty about how they would support someone with dementia because of lack of awareness and experience of the condition.
- 6.41. Fifteen employers stated that they would support an individual who did not have a diagnosis. Five employers felt that a lack of diagnosis made it difficult for them to provide support. However, many also stated that they would be willing to support somebody with or without a diagnosis, because it was 'the right thing to do'.
- 6.42. Twenty employers stated that their organisation had all-encompassing policies or strategies already in place which would help support someone with dementia to remain in work. Most believed their general health and well-being policies were broad and needed to be to support many different kinds of illnesses, conditions, and disabilities. Most employers also did not think a specific dementia policy was required.
- 6.43. Fourteen employers wanted to be involved in awareness raising activities regarding dementia in the workplace in the future. Three employers expressed no interest in getting involved in awareness activities.
- 6.44. Across the interviews, there was a high degree of consistency between the responses from employers and the online survey reported in Chapter 5. This reinforcement of the qualitative results and feedback from the interviews confirms that the attitudes and behaviours in the workplace reported by employers are robust and can be the basis for recommending improvements to practices and processes for businesses and other organisations.

Chapter 7: Conclusions and Recommendations

- 7.1. Whilst it is likely that every workplace will have unique experiences of employees with dementia this study indicated that across Scotland a number of broad and important conclusions can be made upon which certain recommendations can be drawn.
- 7.2. It is clear from persons interviewed on behalf of employers that their own experience meant that in many cases they had a high degree of knowledge of the symptoms and issues associated with living with dementia. However, such knowledge appears have clearly not been gathered from experiences in, or applied to, workplace situations in terms of managing and supporting employees with a diagnosis of dementia or identifying those employees without a diagnosis but possibly displaying signs and symptoms of dementia (see Chapters 5 and 6).
- 7.3. Employers expressed uncertainty about how they would support someone with dementia because of lack of awareness and experience of the condition (see Chapters 5 and 6). Too many employees with dementia are exited from the workplace as a result of being found to be unable to adequately perform the roles required of them or voluntarily leave owing to this (Ritchie et al. 2017). The real continuing potential of employees in the workplace, particularly where appropriate support is provided, is not generally recognised.
- 7.4. There are many examples of employers having experience of supporting workers with other physical and mental health conditions and it was understood that existing policies and procedures relating to these could be adapted for persons with dementia (see Chapter 6). However, it is clear that supporting an employee with dementia needs to be done on a case-by-case basis given the very individualised nature of a diagnosis of dementia and the way in which dementia develops in each person (see Chapter 6).
- 7.5. The type of support provided would therefore very much depend on the role, the progression of the condition and the nature of any impairments attributable to the dementia. Employers considered that dementia might impact on employment including attention to detail and accuracy, cognitive, memory and communication impairments, difficulties coping with an unstructured routine, the pressures of the job, the emotional impact of the dementia and use of technology (see Chapter 6).
- 7.6. Despite employers appearing to recognise in principle that dementia is a disability falling within the scope of the Equality Act 2010, their knowledge of the protection potentially provided to workers with dementia under such legislation, and therefore their legal responsibilities as employers, is low. In particular, there is uncertainty about the stage at which dementia would, or should, be seen as a disability under the Equality

Act 2010 and the precise nature of reasonable adjustments that are required (see Chapters 5 and 6).

- 7.7. Employer knowledge of relevant aspects relating to the requirement for support for the exercise of legal capacity and reasonable accommodation in the workplace, of the United Nations Convention on the Rights of Persons with Disabilities, was virtually non-existent (see Chapter 5) . It is vital that this lack of knowledge of the requirements of relevant law and human rights standards is addressed from the perspective of employers, employees with dementia and those who are dependent on such employees such as family members and co-workers. In particular, it is noted that whilst diagnosis appears to be pivotal in terms of securing Equality Act 2010 protection this is not necessarily a requirement of the United Nations Convention on the Rights of Persons with Disabilities and the importance and influence of this treaty in Scotland is highlighted in Chapter 1 of this report.
- 7.8. Employers have expressed a desire for information and guidance on how to identify the key signs and symptoms of dementia in order to enhance their support and management of employees with dementia, which would add to, or complement, existing core HR, health and well-being policies and procedures.

Recommendations

- 7.9. From these conclusions five recommendations are made:

Recommendation 1

There is a need for increased employer awareness that dementia is a disability and that they therefore have legal and human rights obligations to support employees with dementia.

Recommendation 2

There must be clear guidance and training on the legal and human rights position of employers and employees in relation to dementia in the workplace.

Recommendation 3

There must be clear pathways in workplaces to enable employers to support employees with dementia, or with potential symptoms of dementia, that allows such employees to either continue in employment or to leave it in a dignified manner that fully respects their legal and human rights.

Recommendation 4

In order to effectively implement such pathways there is an urgent need for an integrated approach with management, the employee concerned, Occupational Health, vocational rehabilitation and all others involved in the implementation of the pathways.

Recommendation 5

There is a need for awareness raising amongst health care professionals to consider the implications for employment where a person is diagnosed with dementia.

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Appendices

Appendix 1: Experts in the Field – Interview Questions


(You only need to answer questions relevant to your own area of expertise)

1. What is your role?
2. Have you had any experience of, or contact with, people with dementia in the workplace?
3. Do you think that dementia in the workplace is a concern now, or will be in the future?
4. How could dementia impact on employment?
5. What support is available to enable someone with dementia to stay in employment?
6. Can you tell me about employment policy for people with disabilities in general and how that relates to people with dementia?
7. Can you tell me about the Equalities Act 2010 and the UN Convention on Rights of Persons with Disabilities and how they relate to people with dementia in the workplace?
8. How could someone who has cognitive and/or memory problems, but hasn't yet had a formal diagnosis, be supported in the workplace?
9. Do you know what support is available for employers regarding dementia in the workplace?
10. Do you think that current legislation ensures that employees with dementia are adequately supported in the workplace?
11. Do you think that employers should have their own specific policies to help support people with dementia in the workplace?
12. Would you like to add anything else?


Appendix 2: Employer Online Survey



Edinburgh Napier
UNIVERSITY



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Employer Responses to Dementia in the Workplace

Introduction

You are invited to complete a survey for a study on employer responses to dementia in the workplace in Scotland. The study is being undertaken by a research team from Edinburgh Napier University, the University of the West of Scotland and Heriot Watt University. The research is funded by the Carnegie Trust for the Universities of Scotland.

Why is this survey being carried out?

We would like to understand the extent to which employers are aware of their legal duties and whether they have policies and practices in place to support employees with dementia. We are also interested to know if you think there is a need for further information to improve knowledge about dementia.

How long does the survey take?

This survey will take approximately 15 minutes to complete. Your participation is entirely voluntary. You don't have to answer any questions you don't want to. If there are some questions you can't answer, please don't worry. If you could answer as many questions as possible it would be very much appreciated.

PLEASE NOTE - If you want to go back to a previous question click the 'Prev' button at the bottom of the page, rather than the 'Back' button on your web browser.

How will the information be used?

The information provided by you in this survey will be used for research purposes only. It will not be used in a manner which would allow identification of individual responses. No organisations or individuals will be named in the writing up of the survey findings.

Note that once you submit your response, you will not be able to withdraw it as we cannot link your survey response back to you.

What if I have additional questions?

1

If you have any questions please contact Mandy Cook on: m.cook@napier.ac.uk.

* 1. Do you agree to take part in the survey?

Yes

No

Employer Responses to Dementia in the Workplace

Section 1: Questions about you and your workplace

2. From this list, what best describes the main activity of this workplace?

Other (please specify)

3. Is this workplace a...?

- Public sector organisation (includes local authorities, councils, government departments, civil service, state schools, the NHS)
- Private sector organisation (includes partnerships, private limited companies, family-owned businesses, self-employed)
- Third sector organisation (includes charities and not for profit organisations)
- Social enterprise (includes profit and not for profit)

4. Is this workplace...?

- A single independent establishment
- Part of a larger organisation
- Don't know

5. From this list, in which local authority area is this workplace based?

Other (please specify)

Employer Responses to Dementia in the Workplace

Section 1: Questions about you and your workplace

6. Approximately, how many people are working for this organisation as a whole?

- Less than 10
- 10-49
- 50-249
- 250-999
- 1,000 or over

7. Approximately how many of these people are temporary workers or volunteers?

(Please include volunteers, seasonal workers, casual workers, interns/work placement/unpaid, etc)

- None
- Less than 10
- 10-49
- 50-249
- 250-999
- 1,000 or over

8. Approximately what percentage of the total workforce working for this organisation as a whole are...?

	None	Less than 10%	10% to 20%	More than 20%	Don't know
Aged under 25	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aged 26-49	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aged 50-59	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aged 60-64	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aged 65 and over	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Approximately what percentage of the total workforce are...?

Female

Employer Responses to Dementia in the Workplace

Section 2: Policies, Rights and Practices

10. Does this workplace have any specific policies or strategies for older employees (those aged 50 plus)?

- Yes
 No
 Don't Know

Any Additional Information

11. Does this workplace have any policies or strategies (e.g. for disabled employees) that make reference to or provisions for employees with dementia?

- Yes
 No
 Don't Know

Any Additional Information

12. Does this workplace have any specific policies or strategies regarding the rights of employees who have dementia?

- Yes
- No
- Don't Know

Any Additional Information

13. Are you aware if your organisation has ever undertaken any dementia awareness raising activities with staff?

- Yes
- No
- Don't Know

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 2: Policies, Rights and Practices

14. To what extent do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Employees with dementia are not considered to be a concern for this organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This organisation is increasingly aware of the need to do more to support employees that have dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This organisation already has a policy in place to support employees with dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This organisation is currently reviewing its approach with a view to developing a policy to support employees with dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 2: Policies, Rights and Practices

* 15. Does this workplace have any experience of an employee with dementia?

Yes

No

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 2: Policies, Rights and Practices

16. Did this workplace develop a policy to support employees with dementia because you had someone with dementia working for you?

Yes

No

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 2: Policies, Rights and Practices

17. Does this workplace have experience of employing someone who cares for a person with dementia?

Yes

No

Any Additional Information

18. Does this workplace see dementia as a disability?

- Yes
- No
- Don't Know

19. Does this workplace consider employees with dementia to be protected under the Equality Act 2010?

- Yes
- No
- Don't Know

* 20. Have you heard of the UN Convention on the Rights of Persons with Disabilities?

Yes

No

21. Does this workplace consider employees with dementia to be protected under the UN Convention on the Rights of Persons with Disabilities?

- Yes
- No
- Don't Know

22. To what extent are you aware of the different symptoms of dementia?

- Very aware
- Aware
- Neither aware nor unaware
- Unaware
- Very unaware

23. Do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
Dementia can cause memory loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia can cause difficulty in effective planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia can cause communication problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia can cause confusion over times and places	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia can cause issues with visual perception	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia can cause mood changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Employer Responses to Dementia in the Workplace

Section 3: Support for Employees with Dementia

24. To what extent do you agree or disagree with the following statement:

Employers should make 'reasonable adjustments' for employees with dementia.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

Any Additional Information

25. To what extent do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Employees with dementia should be offered a change in hours/flexible working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered a change in job to take on lighter or less demanding work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered a reduction in workload	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered increased IT support/specialist IT equipment to support them with their work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered extra support from work colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered re-training to be able to do another job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered time off to attend medical appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employees with dementia should be offered counselling or mentoring support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 3: Support for Employees with Dementia

26. To what extent do you agree or disagree with the following statement: An employee should be offered support by their employer if they show symptoms of dementia but have not yet received a diagnosis?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

Any Additional Information

Employer Responses to Dementia in the Workplace

Section 3: Support for Employees with Dementia

27. Where would this workplace seek advice if an employee were to develop symptoms of dementia or be diagnosed with dementia?

Select all that apply

- Specialist consultant
- External lawyers
- Trade Union
- Employers' association
- Occupational health
- Charity/third sector organisation, e.g. Alzheimer Scotland
- Professional body
- Government department or agency
- Healthy Working Lives
- Working Health Services
- Fit for Work Scotland
- Access to Work
- Specialist HR consultant
- Internal HR
- Other internal adviser

Other (please specify)

* 28. Would this workplace welcome information, support or advice to improve knowledge and understanding of dementia in the workplace?

Yes

No

29. What information, support or advice would be useful for your workplace to improve knowledge and understanding of dementia in the workplace?

Select all that apply

- Occupational health and safety needs assessment visits
- Advice and guidance from local employer associations
- Workplace training and awareness sessions on dementia
- One to one support tailored to your workplace
- Focused training/workshop on dementia
- Expert legal advice and guidance
- Paper or web based toolkit guides
- Web information
- Support by email
- Information pack/leaflets
- Free information, support or advice
- Confidential information, support or advice, not involving enforcing authorities

Other (please specify)

30. Are there any topics you feel that this workplace needs help with to support employees with dementia in the workplace?

Employer Responses to Dementia in the Workplace

As part of this research we would like to conduct follow up interviews with employers to explore in more detail support for employees with dementia in the workplace. To conduct these interviews, we would visit your workplace to speak to you and/or other relevant members of staff. Alternatively we could speak to you over the telephone.

31. Would you be interested in taking part in a follow up interview?

- Yes (please provide your contact details on next page)
- No

32. Your contact details

Name

Telephone

Email address

Thank you for taking the time to complete this survey.

If you have been affected by any of the topics raised in this survey you can call the 24-hour Dementia Helpline, which is a freephone Scottish service for people with dementia, carers, relatives, professionals, students and anyone concerned about dementia.



Appendix 3: Employer Interviews – Interview Questions

1. Can you tell me a bit about your organisation and what your role is? Why was your organisation interested in taking part in this research?
2. How easy do you think it would be for your organisation to support someone with dementia at work?
3. Do you think that people with dementia fall within the protection of the Equality Act 2010?
4. Does your organisation have any policies or strategies already in place which would help support someone with dementia to remain in work?
5. Have you been, or would you like to be involved in any awareness raising activities regarding dementia in your workplace?
6. Would you like to add anything else?