**The legal implications of dementia in the workplace: establishing a cross disciplinary research agenda**

**Abstract**

Dementia is a growing issue in the United Kingdom (UK) with over 800,000 people affected. Of these people in excess of 40,000 are aged under 65 years. Thus, a significant number of individuals may be experiencing symptoms of dementia while in employment. In addition, as working lives extend, the potential impact of dementia on the workplace could be substantial. However, to date, there has been little research on experiences of dementia in the workplace. The research that exists highlights the lack of support for workers with dementia. Dementia may be considered to be a disability under the Equality Act 2010. Therefore, the legislation potentially provides a framework for individuals to request that their employer make reasonable adjustments to support their continued employment. International human rights law is potentially another tool that could be utilised to obtain necessary adjustments. This paper argues that in developing the evidence base on workplace experiences of dementia, it is important that the legal framework be considered. This paper reviews the existing literature on dementia in the workplace and embeds this in the legislative framework in order to establish a cross disciplinary research agenda. While the paper focuses on the UK legal context, the argument presented in the paper is still relevant to other national contexts.

**Key words**

Dementia, workplace, older workers, Equality Act 2010, human rights law, cross disciplinary research

**Introduction**

In the United Kingdom (UK) over 800,000 people have dementia. This figure 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). Of the 800,000 people living with dementia, in excess of 40,000 are aged under 65 years (Alzheimer’s Society 2015; Prince et al. 2014). Thus, a significant number of individuals below state pension age may be experiencing symptoms of dementia while in employment. As working lives extend in the UK as a result of increases to the state pension age, the abolishment of the default retirement age and the lack of adequate public pensions, the potential impact of dementia on the workplace could be substantial. Furthermore, government is placing emphasis on a ‘fair’ work agenda, as well as the importance of supporting people with disabilities to remain in the workplace (Fair Work Convention 2016; Robertson, Kirkpatrick and McCulloch 2015). Thus, it needs to be recognised that dementia *is* a workplace issue. Indeed, the first symptoms of dementia are often initially noticed, and/or are noticeable, in the workplace as people may find it difficult to manage new tasks or challenges (Chaplin and Davidson 2016; Ducharme et al. 2013; Johannessen and Möller 2013; McNamara 2014; Ohman, Nygard and Borell 2001; Roach, Drummond and Keady 2016; Tolson et al. 2016). Consequently, employers need to be prepared to support employees with dementia in the workplace. Extending the research base in this area is one-step to achieving this.

To date, there has been little research on experiences of dementia in the workplace. This can be in part explained by the limited research on and with, or services geared toward, people with dementia aged under 65 (Brown and Roach 2010; Clemerson, Walsh and Isaac 2013). However, earlier diagnosis of dementia and the discovery of markers associated with the development of dementia may mean that increasing numbers of younger people will be diagnosed with dementia (Robertson, Kirkpatrick and McCulloch 2015). Therefore, research is needed on the workplace experiences of employees with dementia. The limited research that does exist highlights the lack of employer support for workers with dementia (Ritchie et al. 2015; Tolson et al. 2016). Dementia may be considered to be a disability under the Equality Act 2010. Therefore, the legislation potentially provides a framework for individuals to request that their employer make reasonable adjustments to support their continued employment. International human rights law is potentially another tool that could be utilised to obtain the necessary adjustments. It is in this context that this paper argues that in developing the evidence base on workplace experiences of dementia, it is extremely important and relevant that the legal framework is considered. There has been limited cross disciplinary work between (social) gerontology and law (Doron and Hoffman 2005; Doron, Lowenstein and Biggs 2017), and none, as far as the authors of this paper are aware, concerning dementia in the workplace. This paper reviews the existing literature on dementia in the workplace and embeds this in the legislative framework in order to establish a cross disciplinary research agenda on the legal implications of dementia in the workplace. While the paper focuses on the UK legal context, the argument presented in the paper is still relevant to other national contexts.

**Dementia in the workplace**

There is an extensive research base examining the effects of dementia on individuals and their supporters, addressing issues such as personhood in dementia, how spouses and other family members respond to the impact of dementia and how informal carers for people with dementia negotiate their caring roles (Allen and Oyebode 2009; Ducharme et al. 2013; Egdell 2013; O’Connor et al. 2007). There have been studies of how informal carers balance care demands with those of the workplace (Arksey and Glendinning 2008; Milne et al. 2013; Principi et al. 2014; Schneider et al. 2013) and there is a growing body of work about age management and “age friendly workplaces” (Appannah and Biggs 2015; Ciampa and Chernesky 2013; Conen, Henkens and Schippers 2012; Fuertes, Egdell and McQuaid 2013; Loretto and White 2006; Nicholson et al. 2016; Schröder, Muller-Camen and Flynn 2014; Taylor and Walker 1998). There have also been moves in the dementia studies literature towards using a citizenship model to highlight the agency of people with dementia, social inclusion and power (Baldwin 2008; Bartlett and O’Connor 2007), as well as the foundational work in the field associated with a person-centred approach to dementia (Kitwood 1997; Kitwood and Bredin 1992). However, a notable absence in this body of work is research on the workplace experiences of people with dementia themselves and the need for “dementia friendly workplaces”.

While the research into dementia in the workplace is limited, the research that exists (which has engaged with people with dementia as well as their supporters, employers and colleagues) highlights the lack of support for workers with dementia, issues around work performance and job retention, and the sometimes sudden and/or traumatic cessation of work (Chaplin and Davidson 2016; Ohman, Nygard and Borell 2001; Ritchie et al. 2015; Roach and Drummond 2014; Tolson et al. 2016). This lack of workplace support for people with dementia can be attributed to the general lack of knowledge surrounding the causes, risk factors and prevention, diagnosis, the different types, treatment and effects of dementia (Cahill *et al.* 2015; Friedman *et al.* 2015; Kim, Sargent-Cox and Anstey 2015; Low and Anstey 2009; Lüdecke, von dem Knesebeck and Kofahl 2016). This lack of understanding contributes to stereotyping, stigmatising and infantilising views of people with dementia that may result in negative perceptions about their competence and capabilities (McParland *et al.* 2012; Milne 2010; Werner 2006; Werner, Goldstein and Buchbinder 2010). In addition to the stigma, people with dementia may also experience the combined jeopardy of age discrimination (Milne 2010).

Continued employment post diagnosis of dementia is possible. People with dementia often remain very capable for some time following a diagnosis, but this is not necessarily acknowledged. Having a supportive employer who has a good understanding of dementia is vital (Stephen 2015; Tolson et al. 2016). However, in the main the literature draws attention to poor employer practice, which *‘is, at best, poor and at worst unlawful’* especially for those in lower ranked occupations (Chaplin and Davidson 2016, p. 13). Employers might not consider how adjustments could be made to make the best use of, and retain, the skills of their employees (Chaplin and Davidson 2016; Tolson et al. 2016). Aside from the organisational issue of losing skilled members of staff, at the individual level, the sense of self can be challenged if a person with dementia is forced to leave employment, with workplace identity often the first to be fractured (Harris and Keady 2009; Roach and Drummond 2014). Indeed, the importance of work in supporting the self-esteem and life satisfaction of people with dementia can be illustrated in the development of supported workplace engagement for people with early-onset dementia (Robertson et al. 2013). Being forced to cease work can challenge the dignity of the individual and relationships with others, as well as increasing the financial pressures felt by their families, especially spouses who may become the sole income provider, paying mortgages and supporting dependents (Chaplin and Davidson 2016; Harris and Keady 2009; Ohman et al. 2001; Roach and Drummond 2014; Roach et al. 2009; Svanberg, Spector and Stott 2011; Svanberg, Stott and Spector 2010; Tolson et al. 2016).

**The legal implications of dementia in the workplace**

To date there has been limited cross disciplinary work between (social) gerontology and (elder) law (Doron and Hoffman 2005; Doron, Lowenstein and Biggs 2017). There are exceptions with studies exploring issues such as the status of older people in the European Court of Human Rights, older people’s knowledge about their legal rights, how films portray law or legal issues related to ageing, the European Court of Justice case-law with regards to elder rights, and judicial narratives and ageism (Doron and Werner 2008; Doron 2006a, 2012, 2013; Spanier, Doron and Milman-Sivan 2013). Cross disciplinary studies which have focused upon dementia specifically highlight that in the legal system a diagnostic label of dementia limits the individual's autonomy as a result of paternalistic attitudes and a lack of knowledge about dementia (Werner and Doron 2016).

Israel Doron has been particularly active in arguing the need for those working in the fields of gerontology and elder law to share knowledge and practice. This is important in order that the gaps between the ‘letter of the law’ and lived experiences of older people can be addressed, as well as providing a deeper and more legally situated knowledge of the experiences of older people (Doron and Hoffman 2005; Doron and Meenan 2012; Doron 2006b)*.* Research to date on dementia in the workplace points to the value of taking a cross disciplinary approach and embedding, within the legal framework, the experiences of workers with dementia. Thus, this paper now considers the legal implications of dementia in the workplace.

*The Equality Act 2010*

The Equality Act 2010 offers a potential avenue of support for people who have dementia in employment. It imposes a general duty on employers to make reasonable adjustments where a provision, criterion or practice puts a disabled employee at a substantial disadvantage (HM Government 2010). Failure to comply with this duty constitutes disability discrimination. In order to request reasonable adjustments from an employer, the employee must firstly demonstrate that they come within the definition of disabled as provided for under the Act, that is, they must have a physical or mental impairment and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Research indicates that employees with dementia may not be offered ‘reasonable adjustments’ (although some may be given adjusted duties when their employer becomes aware of their difficulties) because of a lack of understanding about dementia (Chaplin and Davidson 2016; Tolson et al. 2016). Generally, when an employee brings a claim against their employer alleging a failure to make reasonable adjustments, it is claimed that the condition does not come within the definition of disability (Lockwood, Henderson and Thornicroft 2014). This approach necessitates detailed consideration of the claimant’s impairment and its effects, which can be an invasive and upsetting process (Lawson 2011). Where individuals claim that they have a mental impairment like dementia, the stigma often attached to mental illness may make this an even more distressing process (Bell 2015).

There is limited reported case-law on disability discrimination concerning claimants with dementia. However, case-law relating to disability discrimination in the context of mental illness provides some indication of the issues which arise when bringing a claim before the Employment Tribunal. For example, difficulties often arise in establishing that an individual with a mental illness comes within the definition of disabled and that their condition is an ‘impairment’ that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities (Bell 2015; Lockwood, Henderson and Thornicroft 2014; James 2004). In relation to dementia, as it is a progressive condition that is difficult to measure and diagnose (Doron 2014) - possibly due to individuals being hesitant in seeking support, health professionals being reluctant to make a diagnosis, and symptoms in the under 65s being attributed to other causes such as depression or work induced stress (Ohman et al. 2001; Karnieli-Miller et al. 2007; McNamara 2014; Roach, Drummond and Keady 2016; Tolson et al. 2016) - it may present particular challenges in meeting these tests. Nevertheless, in *J v DLA Piper* ([2010] I.C.R 1052) where the Employment Tribunal had to determine whether the claimant suffered from depression and was disabled within the meaning of the Act, it was found that it is the effects of the condition that should be assessed, rather than making the decision *‘on the basis of an exclusively medical diagnosis’* (Lockwood et al. 2014, p. 174). This means that having a medical diagnosis should not act as a barrier to coming within the protection of the legislation. The Act’s Code of Practice confirms that the effect of the impairment should be considered, not the cause (Equality and Human Rights Commission 2011).

Lockwood, Henderson and Thornicroft (2014, p. 174) state that *‘the requirement that the impairment should be substantial and long term also acts as barrier to a claimant success’*. Some guidance is given in the legislation on how these terms should be interpreted. Schedule 1 states that the effect of an impairment is long-term if it has lasted or is likely to last for at least 12 months or for the rest of affected person’s life (HM Government 2010, Sch.1, Para.2(1)). ‘Substantial’ is defined as ‘more than minor or trivial’ (HM Government 2010, s.212(1)). It is therefore uncertain that an individual with a mental illness who is impaired (often seriously) for only a limited time would come within the definition (Lockwood et al. 2014). As outlined above, early stage symptoms of dementia can often be attributed to other conditions; particularly in people with early-onset dementia. As such, it may be that the impairment is not considered to be substantial or long term until more serious or debilitating symptoms appear.

In *May v Secretary of State for Transport* (2015 WL 3875667) the claimant argued that because of his cognitive and memory problems he should be considered disabled within the meaning of the Act. The Employment Tribunal rejected his claim, arguing that the problems he had were minor and trivial and were not as bad as he had described to medical professionals. On appeal, the Employment Appeal Tribunal upheld the initial decision stating that the claimant’s evidence was conflicting and unconvincing. While the claimant in this case did not have a diagnosis of dementia, he had been in contact with specialists who had referred to his memory problems and stated that Alzheimer’s presentation was not excludable. Nevertheless, the Employment Appeal Tribunal was not convinced by this evidence and held that the Employment Tribunal had not misdirected itself in finding that *‘a condition would not qualify as amounting to a disability if it was manifested only in symptoms in ordinary everyday matters’*. This case demonstrates that individuals who are experiencing symptoms, but who do not have a diagnosis of dementia, could face significant obstacles in establishing themselves as a person with a disability. It also highlights that the requirement to fall within the definition of disability places focus on *‘functional limitations’*, rather than on the alleged discriminatory behaviour of the employer (Lawson 2011, p. 362), potentially perpetuating discriminatory attitudes.

There have been calls for the disability definition to be widened by removing the need for the impairment to be long-term and have a substantial effect on day-to-day activities (Fraser Butlin 2011; Lawson 2011). The current definition has resulted in almost a fifth of all disability discrimination tribunal cases failing (Lawson 2011). There are also issues surrounding the accessibility of tribunal procedures. Chaplin and Davidson (2016) have highlighted that it is unlikely that people with dementia would feel confident enough to bring a disability discrimination claim against their employer, signalling the need for further research into reasonable adjustments that enable people with dementia to access justice.

*Employer knowledge and adjustments*

In Lockwood, Henderson and Thornicroft’s (2014) study, it was found that the majority of discrimination claims related to the failure of an employer to make a reasonable adjustment. The employers’ duty only applies if they know, or could reasonably be expected to know, that the worker has a disability and is, or is likely to be, placed at a substantial disadvantage (HM Government 2010, Schedule 8 Para.20). Research has shown that individuals are often reluctant to inform their employers that they have a mental illness due to the stigma that can be attached to disclosing such information (Lockwood et al. 2014). Dementia labelling has been shown to dehumanise and increase the stigmatisation of people with the condition (Werner 2014; Surtees 2014). Employees may even actively try to conceal their mental health issues (Bell 2015) which could potentially have a negative impact on the success of a disability discrimination claim as it can be viewed by the tribunal as lack of cooperation (Lockwood, Henderson and Thornicroft 2014).

Types of reasonable adjustments which employers can make are not set out in the legislation and while the duty has been described as “wide” (Lockwood et al. 2014) recent research has suggested that the Employment Appeal Tribunal is retreating from the expansive approach (Bell 2015). Evidently, adjustments only extend to “work-related” matters and the duty applies only to the extent of adjustments that are “reasonable” (Lockwood, Henderson and Thornicroft 2014). In cases where employers have been found to fail in their obligation, it is often because they did not *‘give proper consideration to the making of changes’* (Lockwood et al. 2014, p. 9). In relation to reasonable adjustments for employees with mental health problems, McDowell and Fossey (2015) find that employers’ knowledge of the possibilities may be limited because they are “less tangible” than adjustments that can be made for people with physical disabilities.

Research has identified a variety of adjustments commonly used to assist people with mental health problems to remain in, or return to, employment. These include: training of other staff in how to support the employee with mental illness; flexible or reduced working hours; different training and supervision arrangements; modified job duties; physical adaptions (e.g. quieter workplace); extra time to complete tasks; working from home; and peer support (McDowell and Fossey 2015). Tolson et al. (2016) who examine the potential for continued employment post diagnosis of dementia identify similar adjustments. Such adjustments could increase the length of time employees stay within their job (McDowell and Fossey 2015) and such adjustments are in keeping with how modern workplaces are being organised (Bell 2015).

*International law*

While the Equality Act in theory provides much needed protection for employees with dementia, it may fail to meet the requirements of international human rights law. The European Convention on Human Rights (Council of Europe 1950) does not identify any relevant rights. Its socio-economic rights counterpart, the 1961 version of the European Social Charter (Council of Europe 1961) which has been ratified by the UK, does provide some comfort in terms of affording disabled persons the right to work, however there is no mention of reasonable adjustments and these rights are in any event not legally enforceable within the UK. The concept of reasonable accommodation is, however, present throughout the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) and was seen as an essential foundation for the realisation of equality for people with disabilities (Kayess and French 2008). It is defined in Article 2 CRPD (United Nations 2006) as *‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’*. Under Article 5 CRPD (United Nations 2006), equality and non-discrimination, states are obliged to promote equality and eliminate discrimination by taking all appropriate steps to ensure that reasonable accommodation is provided. Reasonable accommodation is thereby recognised as an essential aspect of ensuring the realisation of human rights for people with disabilities on an equal basis with others (Lawson 2010).

The concept of reasonable accommodation runs throughout the CRPD, with more specific provisions containing reasonable accommodation requirements. In particular, Article 27 CRPD (United Nations 2006) on work and employment, requires states to safeguard and promote the realisation of the right to work for people with disabilities by ensuring that reasonable accommodation is provided in the workplace. The requirement in Article 12 CRPD (United Nations 2006) that states provide access to appropriate support for exercise of legal capacity is vital for individual autonomy and promotes the rights of people with dementia to be included and participate in society. While similarities can clearly be seen between the CRPD requirements and the Equality Act duty, fundamental differences in how disability is defined means that the scope of these two instruments could vary considerably. The CRPD does not contain a definition of disability as such. However, Article 1 CRPD states that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (United Nations 2006). This definition moves the focus from the person’s impairment onto the societal barriers, which prevent them from fully participating (Fraser Butlin 2011). The Equality Act’s preoccupation with the person’s impairment and its effects situates the UK’s approach to reasonable adjustments firmly in the medical model of disability (Lawson 2011). The medicalisation of disability and requirements to show that the individual is somehow deficient clearly conflicts with the CRPD’s social model, which locates disability in the attitudes and barriers of society. Nevertheless, the concept of reasonable accommodation within the CRPD is not without flaw, and has been criticised for excluding adjustments that are “disproportionate” and impose an “undue burden” (Article 2 CRPD) (United Nations 2006). This characterises people with disabilities as burdensome and could allow states to avoid their obligations, in turn rendering the concept effective only for people who *‘require relatively marginal changes to the prevailing social environment’* (Kayess and French 2008, p. 27).

The close connection between disability and ageing highlights the potential of using the CRPD to secure positive outcomes for people affected by dementia. It provides a benchmark for expanding legal responses to people who retain autonomy, personhood and dignity and who, often with support, can continue to contribute to society (Donnelly 2014; Schmidt 2014). This is also in line with the person-centred approach to dementia care. Exploring the intersection between disability and ageing provides the opportunity to contribute to the current debate on drafting a “convention on the rights of older persons” and to challenge and change attitudes about the capabilities and rights of not only older people, but people affected by conditions associated with ageing such as dementia (Kanter 2009).

While the CRPD is not directly incorporated into UK law, the UK and devolved governments are still bound by their international obligations and should legislate in a way that is compatible with these obligations. Under the CRPD, the UK is required to submit reports at regular intervals for consideration by the United Nations Committee on the Rights of Persons with Disabilities, which sets out the measures taken, and progress made, to give effect to the CRPD. The Committee considers the report and issues suggestions and recommendations. It is therefore important that policies and legislation are considered in light of the requirements of the CRPD and that potential conflict between the UK’s equality law and obligations under international human rights law are given further consideration.

**Setting the cross disciplinary research agenda**

The legal literature highlights that in developing the evidence base on workplace experiences of dementia, it is extremely important and relevant that the legal framework is considered. It highlights, alongside issues underlined in the gerontological literature, a series of questions and themes that should be addressed in this cross disciplinary research agenda. These questions implicate a range of disciplines, involve diverse methodological approaches, and necessitate the engagement of a range of populations.

1. Researchers from gerontology, labour studies, human resources management, organisational behaviour and linked disciplines need to consider the issue that, given the widespread lack of awareness of dementia and the fact that those experiencing symptoms of dementia in the workplace may conceal the difficulties they are experiencing (Chaplin and Davidson 2016; McNamara 2014), do employers consider dementia in the workplace as an issue that affects their organisation, now or in the future? Addressing this question arguably requires large scale quantitative survey work in order that a baseline of knowledge is established, as well as more in-depth qualitative work with employers to unpick their views as to the ways they understand dementia to be a workplace issue.

2. Gerontologists need to collaborate with those working in the area of human resources management, organisational behaviour and linked disciplines to address the question of how can employees be supported to inform their employer that they have dementia, so that reasonable adjustments can be made if they wish to continue in employment? This research would add a valuable dimension to the existing work on age management and “age friendly workplaces”, and develop further the citizenship model and the person-centred approach taken in the dementia studies literature.

3. Researchers from law, gerontology, labour studies, human resources management, organisational behaviour and linked disciplines need to collaborate in order to address the question of what do employers see as “reasonable adjustments” in relation to people with dementia? Both quantitative and qualitative work is needed to understand whether employers perceive employees with dementia as disabled and therefore falling within the protection of the Equality Act 2010. This research will need to consider the issue of whether the definition of disability needs to be widened so that not only those with long-term impairments or those whose impairment which have a substantial effect on day-to-day activities are considered (Fraser Butlin 2011; Lawson 2011).

4. A related issue that needs to be addressed collaboratively by researchers from law, gerontology, labour studies, human resources management, organisational behaviour and linked disciplines is at which point do employers consider people with dementia to be disabled and fall within the protection of the Equality Act 2010? Questions need to be asked as to what is the employer position towards individuals who may experience dementia symptoms but have not received a medical diagnosis? *May v Secretary of State for Transport* draws attention to the fact that individuals with cognitive and memory problems who do not have a diagnosis of dementia could face significant obstacles in establishing themselves as a person with a disability.

Finally, the focus of this paper has been on employees with dementia, rather than those who are self-employed and/or entrepreneurs. Given the rise in self-employment amongst those aged over 65 years (Office for National Statistics 2014) the position of those who are self-employed and have dementia warrants consideration by gerontologists and entrepreneurship researchers, which is separate from the employment rights framework discussed here.

In summary, this paper has highlighted the importance of embedding future research on dementia in the workplace within the legislative framework. Work continues to be central in the creation of a sense of self, and the maintenance of self-esteem and life satisfaction and as such, it is crucial that those who experience dementia while in work, are adequately supported by their employers. However, in order for this to be achieved, more research is needed into experiences of dementia in the workplace, and this research needs to be embedded within the legislative framework.

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