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Citation: Bolger, Emma, Egdell, Valerie and Ritchie, Louise (2023) Dementia in the workplace: the implications for career development practice. *British Journal of Guidance and Counselling*, 51 (1). pp. 74-83. ISSN 0306-9885

Published by: Taylor & Francis

URL: <https://doi.org/10.1080/03069885.2021.1902471>  
<<https://doi.org/10.1080/03069885.2021.1902471>>

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To cite this article: Emma Bolger, Valerie Egdell & Louise Ritchie (2023) Dementia in the workplace: implications for career development practice, British Journal of Guidance & Counselling, 51:1, 74-83, DOI: [10.1080/03069885.2021.1902471](https://doi.org/10.1080/03069885.2021.1902471)

To link to this article: <https://doi.org/10.1080/03069885.2021.1902471>



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Published online: 02 Apr 2021.



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# Dementia in the workplace: implications for career development practice

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## ABSTRACT

The World Health Organization's Active Ageing policy framework highlights the need for economic and social engagement in communities to maintain and promote healthy ageing and quality of life. This framework does not address the needs of those living with long-term health conditions such as dementia. Although continued employment is not appropriate for all, it is possible for many living with dementia. Despite the numerous contributions that career counselling could make to support people living with dementia we found no consideration of the specific career development needs of people living with dementia in the literature. In this paper we outline the key role that career development professionals could play in the multi-disciplinary teams of professionals supporting persons living with dementia.

## ARTICLE HISTORY

Received 17 October 2019  
Revised 20 January 2021  
Accepted 9 March 2021



## KEYWORDS

Dementia; workplace; career counselling; career development

## Introduction

Since 2002, the World Health Organisation has adopted an “Active Ageing” policy framework for promoting healthy and productive ageing (World Health Organisation, 2002). Active Ageing highlights the importance of being engaged in the community, both economically (e.g. through paid work) and socially (e.g. by maintaining relationships or engaging in volunteering activities), to maintain and promote healthy ageing and quality of life. However, the Active Ageing framework focuses on those deemed to be “healthy” (Boudiny, 2013). It does not explicitly consider the needs of those living with long-term conditions such as dementia. National dementia strategies in the United Kingdom (UK) and internationally promote the living well with dementia imperative, but detail on how to achieve this in practice, especially with regards to economic and social engagement, is sparse (Australian Department of Health, 2015; Department of Health, 2009; Public Health Agency of Canada, 2019; Scottish Government, 2017; US Department of Health and Human Services, 2018). This failure undermines the potential for people living with dementia to remain economically and socially engaged in the community in the manner described in the Active Ageing framework.

In 2015, it was estimated that there were 46.8 million people living with dementia worldwide; this is forecast to increase to 131.5 million by 2050 (Alzheimer's Disease International, 2015, p. 22). Dementia is a term that describes a number of progressive neurological conditions such as Alzheimer's disease, vascular dementia and Lewy body dementia (Budson & Solomon, 2016; World Health

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Organization, 2012). Symptoms include memory loss; difficulties with thinking, decision making and problem-solving; sleep disturbance; and impaired visuospatial ability (Budson & Solomon, 2016; Camicioli, 2014; Lyketsos, 2016; World Health Organization, 2012). Although prevalence of dementia increases with age, between 2-10% of all cases of dementia start before the age of 65 (World Health Organization, 2012). Taking the international standard of the working age (15-64 years (OECD, 2018)), this means that many individuals may be experiencing symptoms of dementia whilst in employment. Added to this, individuals are remaining in work for longer than in the past (Thomson, 2018). Dementia is, and will increasingly be, a workplace issue.

Research undertaken in the UK highlights that continued employment might not be appropriate for all employees living with dementia, yet it is possible for many (Ritchie et al., 2018). Indeed UK law, as well as international human rights standards, require that people living with dementia are afforded the right to employment on an equal basis with others and are supported through reasonable accommodations/adjustments (Egdell et al., 2018). However, research from a number of different national contexts (Australia, Sweden, UK, United States of America (USA)), highlights that the continued labour market participation of people living with dementia, facilitated by reasonable adjustments or redeployment, may not be considered and as such, employers may fail to meet their legal and human rights obligations (Andrew et al., 2019; Chaplin & Davidson, 2016; Egdell et al., 2021; Ritchie et al., 2018; Williams et al., 2018). Many individuals leave the workplace before, or on receipt of, a diagnosis of dementia. Employer expectations about the capabilities of people living with dementia may undermine their skills and experience (Egdell et al., 2021; Williams et al., 2018). The campaigning and activist roles undertaken by some people living with dementia demonstrate that these assumptions are unfounded (Bartlett, 2014; Weaks et al., 2012). Indeed, it is well established within the (social) gerontology literature that people living with dementia have the capability and willingness to contribute to society, and have enriched post-diagnosis lives (Beard et al., 2009). The workplace exits of people living with dementia are often poor, compromising dignity and self-esteem, and placing great financial pressures on households as a result of a sudden decline in income (Harris & Keady, 2009; Ohman et al., 2001; Ritchie et al., 2018; Roach et al., 2016; Roach & Drummond, 2014).

Despite the numerous contributions that career development professionals could make to support people living with dementia, and the likelihood (for the reasons detailed previously) that careers professionals working in lifelong guidance organisations will have clients living with dementia within their caseloads, there has been no consideration that we are aware of the specific career development needs of people living with dementia. In this paper we outline the role that career development professionals could play – alongside a multi-disciplinary team of professionals including psychiatrists, general practitioners, social workers, occupational health workers, dementia specialist support workers, community psychiatric nurses, third sector support workers – in supporting persons living with dementia. When continued employment is not possible, the role of careers practitioners in the range of decisions that extend beyond the cessation of work are reflected upon.

The remainder of the paper is structured as follows. The evidence base of the employment experiences of people living with dementia is detailed. The potential role of career guidance in developing person-centred coping strategies for people living with dementia is explored. The potential challenges related to current career development practice are also detailed.

## **Workplace experiences of dementia**

Awareness of dementia as a workplace issue is gaining currency internationally with dementia support and research organisations (e.g. in Australia, Canada and the UK) publishing employer guides about how to support employees living with dementia (see for example Age Scotland, 2016; Alzheimer Society of Ontario, 2017; Alzheimer's Australia, 2017; Alzheimer's Society, 2015). Nevertheless, given the recognition that people living with dementia have the capability and willingness to contribute to society and have enriched lives (Beard et al., 2009), there is surprisingly little

research on the workplace experiences of people living with dementia, and none, as far as we are aware, on the career guidance needs of people living with dementia.

The extant research on the workplace experiences of people living with dementia in the UK highlights the potential for continued employment post-diagnosis (although it may not be suitable for all people living with dementia) and the national legal and international human rights imperative to support employees living with dementia (Egdell et al., 2018; Ritchie et al., 2018). For many, the symptoms of dementia are often (initially) noticed in the workplace, for instance, as a person slower in completing tasks (Andrew et al., 2019; Chaplin & Davidson, 2016; Evans, 2019; Ohman et al., 2001; Ritchie et al., 2015; Ritchie et al., 2018; Williams et al., 2018). Symptoms that have a detrimental effect on employee performance might not be attributed to a pathological cause such as dementia and an individual can be perceived as a “poor worker” (Andrew et al., 2019; Evans, 2019; Ohman et al., 2001; Ritchie et al., 2018). International evidence (Australia, Sweden, UK, USA) suggests that employers may not have the awareness that dementia is a workplace issue, policies to support employees living with dementia may be lacking, and adjustments that could facilitate the continued employment of the individual might not be put in place (Andrew et al., 2019; Chaplin & Davidson, 2016; Cox & Pardasani, 2013; Egdell et al., 2021; Ritchie et al., 2018; Williams et al., 2018). The consequences of this lack of support results in a workplace exit for many employees living with dementia. Individuals may either be forced to leave work when they disclose their diagnosis of dementia to their employer or will have left work before diagnosis because of increasing stress and deteriorating performance (Andrew et al., 2019; Chaplin & Davidson, 2016; Ritchie et al., 2018). This unplanned and/or sudden loss of a job has detrimental social, emotional and financial effects for the individual and their family (Harris & Keady, 2009; Ohman et al., 2001; Ritchie et al., 2018; Roach et al., 2016; Roach & Drummond, 2014).

People living with dementia are portrayed as dependent, ineffective and unequal citizens, thus limiting rather than enhancing their lives is justified (Baldwin, 2008; Bartlett, 2014, 2016; Beard & Neary, 2013; Brannelly, 2016; Milne, 2010; Swaffer, 2014). As such, their capabilities to work and/or engage in meaningful activities are undermined. This not only has negative implications in terms of the quality of life, but also limits opportunities for the economic and social engagement of people living with dementia. Recent UK-based research by Ritchie et al. (2018) demonstrates the potential for continued employment post-diagnosis, although the complexity of managing this for the employee, employer, colleagues and families should not be underestimated. However, internationally the support offered for employees living with dementia is limited (Mayrhofer et al., 2018; McCulloch et al., 2016) and there is a lack of consensus on the practicalities of how to enable continued employment. Influencing factors include individual coping strategies; dementia symptomatology; the abilities that the individual has retained and the fit of these abilities with the job description; possible person-centred workplace adjustments; and support from families, co-workers and management (Egdell et al., 2021; Ritchie et al., 2018; Williams et al., 2018). There is also often a pre-diagnosis period where the symptoms of dementia begin to impact workplace performance (Evans, 2019; Ohman et al., 2001; Ritchie et al., 2018; Thomson et al., 2019) where early-stage support could prevent a premature workplace exit. The role that career development professionals could play in supporting people living with dementia is considered next.

## Framing dementia as a career guidance issue

The European Lifelong Guidance Policy Network (ELGPN, 2014, p. 25) defines lifelong guidance as:

A range of activities that enables citizens of any age and at any point in their lives to identify their capacities, competences and interests, to make educational, training and occupational decisions and to manage their individual life paths in learning, work and other settings in which these capacities and competences are learned and/or used.

Guidance has social and economic outcomes including reducing labour market exit, increasing tenure, addressing skills mismatch and supporting social inclusion and/or equity (ELGPN, 2014;

Hooley, 2014). Given the limited existing support offer (Mayrhofer et al., 2018; McCulloch et al., 2016) there exists a space in which career guidance professionals can engage and empower employees living with dementia, and those supporting them, to recognise their transferable skills and experience; make informed career decisions; and retain employment and/or seek alternative paid employment or unpaid occupation (e.g. voluntary work, community activities). Lifelong career guidance enables individuals to make informed career decisions relating to both vocational and social aspects of their lives. Not least, the benefits of good guidance can be felt beyond the individual, extending to family members, the workplace and wider society (Hooley, 2014).

Framing dementia as a career development issue correlates strongly with the literature which emphasises the citizenship of people living with dementia (Bartlett, 2016; Bartlett & O'Connor 2007; Brannelly, 2016) and the Active Ageing framework (Boudiny, 2013). Increased attention has been paid by career development professionals to the inclusion of disabled people and those who have long-term health conditions in meaningful work and the role that work plays in identity formation (Dahlbeck & Lease, 2010; Soresi et al., 2008; Wöhrmann et al., 2014). The sense of self and identity can be challenged if a person living with dementia is forced to leave employment (Harris & Keady, 2009; Roach & Drummond, 2014) and supported workplace engagement for people living with early-onset dementia has even been developed to support self-esteem and life satisfaction (Robertson et al., 2013). In-work career guidance intervention in this context, if it enables people living with dementia to remain in work, aligns well with the currently prominent social justice agenda within the career guidance field (Hooley et al., 2018). Within the employment context, people living with dementia take the position of a powerless, marginalised group deserving of socially transformative and emancipatory guidance practice (Hooley & Sultana, 2016). Career guidance could play a key role in developing person-centred coping strategies and workplace adjustments; supporting workplace exits that do not compromise dignity and self-esteem; and supporting people living with dementia to live lives that they have reason to value beyond the workplace. Career guidance in itself may have the potential to improve general well-being in a range of spheres, not limited to work-role satisfaction, but also incorporating broader social aspects (Robertson, 2013).

In taking a lifelong view of career guidance that extends to transitions out of the labour market, career development practitioners clearly also have a role in supporting people living with dementia to make informed career decisions to leave work and to seek unpaid occupation (e.g. voluntary work, community activities) if desired. Indeed, increased attention has been paid by career development professionals to the needs of older workers, including motivation to continue working as well as retirement intentions and adjustment (Boveda & Metz, 2016; Chen, 2011a, 2011b; Hooley, 2014; Lichtenhaler & Fischbach, 2016; Lytle et al., 2015a; Lytle et al., 2015b; McMahan et al., 2010; Templer et al., 2010; Topa & Alcover, 2015). The cessation of work and/or start of retirement involves a range of personal, social and economic considerations/decisions (Furunes et al., 2015; Hooley, 2014; Lytle et al., 2015a; Lytle et al., 2015b; Mitton & Hull, 2006; Wöhrmann et al., 2014) that can be supported by career development interventions (e.g. guidance interviews, group work, career planning tools). Retirement is a process, rather than a fixed-point event, that may have multiple meanings (Alcover, 2017; Boveda & Metz, 2016; Lytle et al., 2015a; Lytle et al., 2015b). It may be precipitated by a range of factors, including poor health (Chen, 2011b; Templer et al., 2010). Counselling for those making the retirement transition needs to account for this – but to date, as far as we are aware, the career development literature has not considered retirement transitions that have been precipitated by dementia. However, it has long been accepted that career decision points often occur prior to, and during the time of, marked transition, such as a new role or when an existing role changes substantially (Super, 1980). Dementia forces such a transition point on an individual; with individuals forced to leave work by their employer upon disclosure of a diagnosis of dementia for example (Andrew et al., 2019; Chaplin & Davidson, 2016; Ritchie et al., 2018). In cases where ill-health has motivated the transition, counselling needs to support clients to make the adjustments required in this context (Chen, 2011b).

## Implications of dementia in the workplace for career development practice

Current career guidance practice must be assessed for its validity and its appropriateness of use with individuals living with dementia. For the popular constructivist approaches to person-centred career guidance (e.g. Maree, 2019; McMahon & Patton, 2006; Savickas, 2012), dementia creates an additional layer in the subjective interpretations the client makes of their own life story and identity during a career discussion. These guidance models require the enabling of a narrative based on the micro-stories of the individual, prompted by a career construction interview model. Constructivist guidance tools and techniques imply an engaged and participative client and a facilitative role for the practitioner. This speaks to arguments that people living with dementia should be viewed as effective and equal citizens (Baldwin, 2008; Bartlett, 2014, 2016; Beard & Neary, 2013; Brannelly, 2016). However, in the utilisation of a constructivist model there is evidence that the recall of early memories has a strong impact on the ability of a client to reflect and effect change in their current situation (Hartung & Vess, 2016). A narrative based on memory may limit or enhance the effectiveness of this approach for some clients living with dementia depending on the pathology, symptomology and disease trajectory (Budson & Solomon, 2016; Camicioli, 2014; Lyketsos, 2016; World Health Organization, 2012). Given the trajectory of dementia, this raises questions of should career development practitioners be working with the client as they are “now” or as they “were” or how they might be in “the future”? The constructivist approach certainly warrants application to this client group, particularly because people living with dementia may have trouble with imagining their future self (Caddell & Clare, 2011). A narrator’s reliability might be questioned but countered by the retention of locus of control. Storytelling throughout the lifespan also links to lifestage models (Super, 1980, 1990), which in their enduring application offer the ability to use generalised career stages.

Decision-styles approaches may be relevant when supporting individuals living with dementia. Individuals make career decisions in different ways, with Bimrose and Mulvey (2016) defining them as strategic, evaluative, aspirational and opportunistic. Gati et al. (2010) argue for a more holistic range of career decision-making profiles that focus on wider characteristics and encompass the present situation. The appropriateness of the decision-styles approach would depend on the symptomology experienced by an individual client living with dementia, as symptoms may include difficulties with decision making (Budson & Solomon, 2016; Camicioli, 2014; Lyketsos, 2016; World Health Organization, 2012). Close working ties between the career guidance professional, the person living with dementia, and other members of the multidisciplinary teams supporting the individual would be key in ascertaining whether the decision-styles approach would be appropriate. We are keen to stress that career guidance professionals should not be expected to make this evaluation unsupported.

The delivery of a guidance intervention also requires examination in this context. The practitioner may need to reconcile the expectations of the client, their family members, their employer and their colleagues with contemporary guidance approaches as well as the applications professional of codes of practice and ethical guidelines (such as, the UK-based Career Development Institute (2019) Code of Ethics and the International Association for Educational and Vocational Guidance (2017) Ethical Standards) that will guide the work of career development professionals in this respect, until specific guidance is available. Whether individuals who are in work perceive contemporary career guidance as personally accessible or relevant (i.e. the demand for career development support) also warrants consideration (Hooley, 2014; Mitton & Hull, 2006). Taking the UK as an example, each nation delivers its own guidance service. Primarily targeted at young people and those in receipt of out-of-work welfare provision, careers services are often generalist rather than specialist. The Scottish Government Career Strategy (currently under review) delivers an all-age service targeted at those needing support in relation to work and learning underpinned by a statutory duty for service provision for those in education and other target groups as required (Scottish Government, 2011) creating a focus on, but not limited to, children and young people and adults who

are out of work or facing redundancy The Career Strategy for England promotes support being available to adults who most need it, with a focus on individuals securing work or upskilling, with a through-line of economic benefit (UK Government, 2017). Similar policies exist for Wales, wherein a focus is repeated throughout on adult re-entry into the workforce (Welsh Government, 2017) and Northern Ireland, where explicit mention is made of the need for support to manage unplanned career change (Northern Ireland Assembly, 2016). Although none of the strategies extend to the naming of specific groups, in all policy documentation there is the potential to interpret the strategy guidance as extending to underrepresented groups at risk of social exclusion, which could include the individual living, and potentially working, with dementia. Careers services being reactive to policy should not exclude individuals living with dementia. We argue that with an ageing workforce, we need to be more cognisant of resourcing and targeting bespoke services throughout the lifespan as an explicit equality focus in the extension of existing quality assurance measures for career guidance (Hooley & Rice, 2019).

## Conclusion

Taking, as a point of departure, the World Health Organization's (2002) Active Ageing policy framework that highlights the importance of economic and social engagement in later life, in this paper we have considered the role of career development practice in supporting the people living with dementia in the workplace. Although continued employment is not appropriate for all those living with dementia, it is possible for many (Australian Department of Health, 2015; Department of Health, 2009; Public Health Agency of Canada, 2019; Ritchie et al., 2018; Scottish Government, 2017; US Department of Health and Human Services, 2018). At present however, many individuals leave the workplace before, or on receipt of, a diagnosis of dementia, and the employment support offer is limited (Mayrhofer et al., 2018; McCulloch et al., 2016). Career development professionals at present, as far as we are aware, do not play a role in the multi-disciplinary team of professionals (including psychiatrists, general practitioners, social workers, occupational health, link workers, community psychiatric nurses and third sector support workers) supporting people living with dementia. It has been demonstrated in this paper that career development professionals could make a valuable contribution to support people living with dementia to remain in work, as well as supporting the range of decisions that need to be made during the cessation of work. Given the damaging effects that an unplanned workplace exit has on the social, emotional and financial wellbeing of a person living with dementia and their family (Harris & Keady, 2009; Ohman et al., 2001; Ritchie et al., 2018; Roach et al., 2016; Roach & Drummond, 2014) the support of career development professionals during this transition could be particularly beneficial.

Career guidance is a lifelong process that supports the social and economic inclusion of individuals (ELGPN, 2014; Hooley, 2014). Career guidance interventions for people living with dementia, if it enables them to remain in work, speaks to the social justice agenda (Hooley et al., 2018) and emphasises the importance of supporting the inclusion of persons with disabilities and long-term health conditions in meaningful work (Dahlbeck & Lease, 2010; Soresi et al., 2008; Wöhrmann et al., 2014) within the career guidance field. Framing dementia as a career development issue also correlates strongly with the recognition of the role played by career development professionals in supporting older workers with retirement intentions and adjustment, including retirement precipitated by poor health (Boveda & Metz, 2016; Chen, 2011a, 2011b; Hooley, 2014; Lichtenthaler & Fischbach, 2016; Lytle et al., 2015a; Lytle et al., 2015b; McMahan et al., 2010; Templer et al., 2010; Topa & Alcover, 2015). However, current career guidance practice needs to be assessed for its validity and appropriateness of use with clients living with dementia. The adoption of constructivist approaches to person-centred career guidance (Maree, 2019; McMahan & Patton, 2006; Savickas, 2012) or decision-styles approaches that emphasise the individual's wider characteristics (Gati et al., 2010), align with arguments made that people living with dementia are effective and equal citizens (Baldwin, 2008; Bartlett, 2014, 2016; Beard & Neary, 2013; Brannelly, 2016). Nevertheless,



narrative based on memory and/or decision-making skills may present challenges for some clients depending on pathology, symptomology and disease trajectory (Budson & Solomon, 2016; Camicioli, 2014; Lyketsos, 2016; World Health Organization, 2012). Added to this, access barriers in terms of people living with dementia perceiving career guidance as relevant for them also needs to be overcome (Hooley, 2014; Mitton & Hull, 2006).

These challenges could be addressed through close working between the career guidance professional, the person living with dementia, and members of the multidisciplinary teams supporting the individual – indeed we would argue that career guidance professionals should be viewed as members of this team. Career guidance professionals should not be expected to assess the appropriateness of specific career guidance practice and/or interventions for clients living with dementia unsupported. Rather targeted and bespoke services that are embedded within the wider multidisciplinary teams supporting individuals living with dementia to ensure the delivery of person-centred career development support is required. The practitioner needs to work with the expectations of the client, their family, their employer and their colleagues and may need to work with others to support and advocate for the client. Consideration of the specific needs of the client living with dementia in conjunction with the broader needs of older workers and disabled workers is also required. Resource professionals need to be trained to understand the impact of dementia and freelance careers professionals need to be open to working with *any* individuals in employment.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

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