Career guidance throughout the lifespan: Working with clients with dementia

Although there has been increased attention on the support needs of older workers and disabled people, up until now there has been a lack of consideration of the career guidance needs of people with dementia.

Dr Laura Lebec, Research Fellow and Dr Louise Ritchie, Reader, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland.

Between 2% and 10% of all cases of dementia start before the age of 65, which means that in many countries a significant number of individuals may experience symptoms of dementia whilst in employment. As dementia is a growing workplace concern, what role could the career development practitioner play in supporting employees who have been diagnosed with dementia?

What is dementia and who is affected by it?

Whilst many people are diagnosed with dementia in later life, a proportion of people will receive their diagnosis while they are under the age of 65 and are therefore likely to still be in employment. A diagnosis under the age of 65 (usually referred to as young or early onset dementia), coupled with a worldwide trend towards later retirement ages and increased life expectancy, means that dementia will inevitably become more common in the workplace.
Dementia and employment
Dementia is therefore increasingly a workplace concern. Employers, however, may not always make the necessary adjustments to enable the continued employment of the individual diagnosed with dementia, should they wish to remain in the workplace. The employer could have low expectations of the capabilities of their employee, and as a result people with dementia can receive a poor, and possibly unjustified, exit from the workplace. This can lead to a loss of a sense of identity for a person living with dementia, as well as having a further negative impact on them financially and emotionally. A person who receives a diagnosis of dementia in their forties, fifties or sixties may be in relatively good physical health and with family responsibilities.

Our research at the Alzheimer Scotland Centre for Policy and Practice and the University of the West of Scotland and that of researchers across the UK and beyond has shown that continued employment for people living with dementia is a viable option; many individuals may wish to continue working and have the capability to contribute to society and live purposeful lives. Although it is recognised (Bolger, Egdell and Ritchie, 2021) that dementia is a workplace issue, we have noted that the existing research highlights the lack of employer support for the employee living with this condition. We have also observed little consensus on the adjustments that are needed to successfully support an employee living with dementia. The complexity of managing this is likely to be significant, and will involve the employee, the employer, their family, and workplace colleagues alongside a multi-disciplinary team of professionals.

The Role of the Career Development Practitioner
In our work, we have identified how the career development practitioner has not been considered as a part of this multi-disciplinary team of professionals. Good career guidance helps individuals to make informed career decisions over the whole of their lifetime. At the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland we are exploring how this could happen in practice for clients with dementia.

Our research team is leading a three year study with stakeholders, including people with dementia, employers, health professionals and career development practitioners. Our aim is to produce a practical guide to support employers and people in employment with dementia to consider how career guidance can help manage employment transitions. In the next section we offer some practical ideas about how you can support clients with dementia.

Supporting clients with dementia
Recognise transferable skills and prior work experience:
A career development practitioner can support a client who has dementia to continue to make informed career decisions. This could mean that the person with dementia may
consider staying in their current role, with adjustments, or seek alternative paid employment or an unpaid occupation.

**Acknowledge lifelong experiences:**
Career guidance should be holistic and life-long and offer a relevant intervention regardless of the life experiences of any client. Considering the client’s earlier life and work experience may be as helpful as discussing their most recent employment.

**Advocate for workplace adjustments:**
The support a career development professional can offer goes beyond one-to-one guidance, meeting the expectations of our professional codes. Career guidance can play a role in person-centred approaches to workplace adjustments and developing necessary coping strategies. When supporting a person with dementia who is considering remaining in their current role, you can positively engage with employers to enable and support continued adjustments. While the range of those adjustments will necessarily vary, it is important to be aware of new tools that become available, particularly in relation to technology, that could be explored.

**Transition to alternative occupations or retirement:**
Leaving any workplace is a critical transition point in a person’s life and career guidance counselling can help people make the required adjustments, especially when this has been driven by a health issue, such as dementia. Where someone is considering seeking alternative paid employment, or an unpaid occupation, the career development practitioner can enable the client with dementia to make an informed decision about their options and create a plan for the future. The career development practitioner could be an active support if the person is considering a decision to leave the workplace through retirement.

**Career guidance throughout the lifespan:**
With an ageing workforce career development practitioners and policy makers need to be more aware of targeting services throughout the whole of a person’s lifespan. Career guidance may not always be on the radar of adults, or older adults, as it is perceived to be something that takes place early in a career, and career guidance practitioners taking on this role can contribute to shifting traditional views around what role career guidance serves. As career development professionals we should seek to promote that career information and guidance can be considered throughout a person’s whole life, not just at major transition points.

**Individual needs:**
The coping strategies which a person will need will vary and support will have to be carefully planned to address the activities the individual needs to carry out in line with their capabilities. Taking a person-centred approach, where the focus is on the person and what they can do, rather than their condition, will be critical.
Self-care for practitioners:
Working closely with a client who has dementia can be personally challenging, particularly if you have encountered dementia in your own family, friend or workplace networks. It is important to ensure that you have good supervision and support in place as a practitioner to help you understand your own reactions and experiences of working with this client group.

A key role
In our research, our aim is to raise awareness of this important topic. We believe that with better promotion of career guidance as being relevant across the lifespan, career development professionals are more likely to meet clients who have dementia.

Career guidance is known to improve general wellbeing and can be considered a non-therapeutic intervention (Robertson, 2013). Furthermore, career guidance for people living with dementia aligns well with the social justice agenda which is prominent in the field today. There is certainly a space for career guidance professionals to play a key role with employees living with dementia, whether that is to enable and support continued employment, or to leave their employment, in an inclusive and respectful way.

We hope this article will encourage reflection on the potential for career guidance practice to support people at different ages and stages of their lives and around the specific challenges that may arise.

Guest editor Dr. Emma Bolger, lecturer and program manager for the Master's program in Career Guidance and Development at the University of the West of Scotland, processes and edits the texts.

Summary:
Employers have a legal and human rights obligation to support employees with disabilities, including those living with dementia, but many may fail to do so.

People living with dementia can find themselves as a marginalised and powerless group. Remaining in employment is, however, possible, and many employees living with dementia may wish to continue in their existing role or seek alternative employment.

Support from families, colleagues, management, and a multi-disciplinary team of professionals is essential, and the career development practitioner, we argue, should form a key part of this supporting team.
**Dementia Fact 1**

The term 'dementia' describes a range of symptoms that, over time, can affect memory, problem-solving, language, vision, and behaviour.

Alzheimer's disease is the most common type of dementia, affecting more than half of those diagnosed.

Other types of dementia include vascular dementia, dementia with Lewy bodies (DLB) and frontotemporal dementia.

The conditions are all usually progressive and eventually terminal.

---

**Dementia Fact 2**

**Worldwide**

People living with dementia: 47 million  
People living with dementia under the age of 65: Estimated around 9% of people diagnosed with dementia


**Scotland**

Population: 5.4 million  
People living with dementia: 90,000  
People with dementia under the age of 65: 3,000

Source: Alzheimer Scotland, 2014

**Norway** *

Population: 5.4 million  
People living with dementia: up to 100,000  
People living with dementia under the age of 65: 4,000

* There is reason to believe that these figures are somewhat low, both because general life expectancy has increased and because life expectancy in Norway is somewhat higher than in Europe and the rest of the west.

Source: [Norwegian Institute of Public Health](https://www.veilederrforum.com), (Published 2015, updated 2019)
Links to further reading


Alzheimer Scotland Centre for Policy and Practice: https://www.uws.ac.uk/research/research-institutes-centres-groups/alzheimer-scotland-centre-for-policy-and-practice/

Our Project: https://linktr.ee/ASCPP_Career_and_Dementia