

Co-Produced Career Guidance Intervention for People Living with Dementia: Guidance for Life, Work and Career

Summary Report



INTRODUCTION

People living with dementia should be supported to make informed, person-centred decisions about their working lives which includes choosing to remain in employment, transition to alternative roles, explore volunteering, or retire. However, research shows that many people with dementia in work report having received little or no advice about their employment and often have a negative experience of work after their diagnosis and experience poor mental health after leaving work.

Having the opportunity to continue working contributes to an individual's wellbeing. Currently, there is a lack of support services for people who are working when they develop dementia. Career guidance is a professional service that assists people with employment-related decisions throughout their career, from leaving school until after they retire. Using a range of person-centred approaches, it can provide individuals with the tools to recognise their abilities, experience and transferrable skills. This research project explored how career guidance could support people living with dementia with employment related decisions.

RESEARCH AIM

The aim of this research was to co-produce and field-test an innovative career guidance and development approach to supporting people living with dementia post-diagnosis. The specific objectives for the research were to:

- 1 Scope current practice around supporting people living with dementia to retain employment or to seek alternative employment or unpaid occupation.
- 2 Explore and imagine the role that career development professionals could play in supporting people living with dementia with employment-related decisions.
- 3 Understand the potential outcomes for people living with dementia in engaging with career guidance tools and techniques.
- 4 Work collaboratively with people living with dementia, career development and health and social care professionals to co-produce a career guidance approach for people living with dementia.
- 5 Field-test the career guidance intervention with post-diagnostic service providers and career development professionals.

METHODS

The methodology for this collaborative research project followed a three-phase co-production model developed by Hawkins and colleagues (2017), which is based on Transdisciplinary Action Research (Stokols, 2006). This means working collaboratively beyond the traditional academic boundaries. It means people with lived experience, practitioners and other stakeholders working alongside academic researchers to develop a shared understanding and co-create solutions. This helps ensure that the research is more likely to lead to practical, meaningful change and is often used in social and healthcare settings (Lingard et al., 2008).

The key activities carried out in each of the three phases of the research are highlighted in figure 1.



Figure 1: Overview of research methods

PHASE 1:

Key Findings from Scoping Review and Stakeholder interviews

Alongside a literature review, stakeholder interviews were held with 20 participants, including people with dementia, carers, career guidance professionals, health and social care staff, and others with relevant experience. These interviews explored current support, the role of career guidance, and how it could be adapted to meet the needs of people with dementia. The key findings were:

- Supporting continued employment for people living with dementia can be complex and may change as their condition progresses.
- The employment experiences of people with dementia are influenced by a number of different barriers and supportive factors.
- While some participants could see the value of career guidance for people with dementia, for the many the term 'career guidance' felt inappropriate, because of the perceived links between dementia diagnosis and the end of career.
- However, there was a recognition that the end of a career is as important as a beginning and there was consensus that career guidance could be adapted for all life stages, including for those living with dementia.
- It was highlighted that the person-centred planning tools and techniques used in career guidance could be especially useful in supporting people through changing life circumstances like a dementia diagnosis.

PHASE 2:

Key Findings

The co-production group consisted of 5 people living with dementia, 2 family carers, 2 career guidance professionals, 6 health and social care professionals and two members of the research team. Over five meetings the co-production group learned, listened and discussed the findings of stage 1 and their own experiences to co-produce a new approach to career guidance for people living with dementia.

Meetings were recorded on MS Teams, and, in addition, a digital graphic recorder was in attendance to create graphic illustrations of each meeting. An example of this is provided in figure 2. The graphic illustrations provided accessible representations of the meetings and were used as reflective tools to recap and develop a plan for next steps.

The key outcomes from the co-production meetings were:

- The co-produced career guidance approach is called 'Guidance for Life, Work and Career'. This was agreed to reflect the changing experiences and perceptions of work and career post diagnosis of dementia.
- There are three parts to the Guidance for Life, Work and Career approach as shown in figure 2. We developed three main supporting materials for the approach. These are:
- A document entitled 'Guidance for Life, Work and Career' providing an accessible overview of the process, incorporating an example career management plan.
- A film made by Skills Development Scotland called 'What a Careers Adviser Does' (5 minutes)
- A film entitled 'Dementia in the Workplace' co-produced by members of the co-production group (17 minutes long)
- Four of the group members living with dementia trialed the Guidance for Life Work and Career approach, this, along with the expert review helped us to refine the approach, identify the practicalities around the meeting as well as the range of potential outcomes.
- All co-production group members shared positive feedback about working together, highlighting strong relationships, mutual respect, and equal involvement.

Figure 2: Graphic illustration from final co-production group meeting



PHASE 3:

Key Findings from Field testing the Guidance for Life, Work and Career Approach

We recruited six people living with dementia who had been recently diagnosed, under the age of 70 to participate in the field-test. They were matched with trained careers advisers, who had not participated in the co-production phase, for one-to-one guidance sessions. Before and after these sessions, participants were interviewed to explore their experiences and perceptions. The careers advisers were also interviewed after the sessions. The interviews were analysed, and two key themes were identified to describe the outcomes of the Guidance for Life, Work and Career Approach. These were:

1. (Re)finding Purpose

- Having a sense of purpose was important to participants, as was maintaining a daily structure and staying active
- Work was closely tied to identity for many and continuing to work or volunteer helped them to remain connected and promoted a sense of usefulness, fulfilment and belonging.
- Guidance helped participants reflect on their life history, focusing on their strengths and contributions rather than limitations and losses.
- Guidance helped participants to set goals, create routine and action plans and make practical decisions, which helped them regain [or maintain] control of their lives and rebuild their confidence.

2. Moving Forward

- Guidance helped participants look ahead with more hope, even if they were still coming to terms with their diagnosis.
- All the participants who completed the field test found the sessions helped them to see that life could still be meaningful and active.
- Career guidance helped participants identify new paths, such as volunteering, further education, or new connections within their community.
- It gave them time and space to reflect, make decisions, and feel supported emotionally and practically.

INVOLVEMENT OF PEOPLE LIVING WITH DEMENTIA

Key to the success of this project was the involvement of people living with dementia at all stages. In line with the overall aim and values of this project, it was important that people living with dementia were provided with opportunities to meaningfully engage and work alongside the research team. Members of the Scottish Dementia Working Group have been involved in this research from informing the development of the research funding application in 2019, through to the creation of this final report. From the project start in 2021, five people have consistently inputted into this work, Margaret Northedge, Kenny Moffat, Margaret McCallion, Rynagh Flynn and Stuart Dougall. From phase 2 onwards, Barry Northedge joined our team to support his wife, Margaret, and to provide input from a family carer perspective. Some examples of the contributions of our co-researchers include:

- Active members of the co-production and stakeholder advisory groups
- Planning, storyboarding and filming our Dementia in the Workplace film
- Co-writing and co-presenting dissemination materials, including blogs and conference presentations
- Developing interview schedules for field test interviews
- Carrying out interviews with field test participants
- Consulting on the analysis of phase 3 data
- Co-producing the final report and dissemination plan for the project.

Throughout the project, the contribution of our co-researchers with lived experience has been insightful, generous and respectful. Their involvement has significantly shaped the direction and depth of this research, and we are very grateful for their commitment. We also extend thanks to our partners at the Alzheimer Scotland Active Voice team, especially Wendy Rankin-Smith, for their support in making this collaboration possible. Contributions to the project were remunerated in various ways, including vouchers, and reimbursement for conference attendance and travel.



Figure 3: Members of the research team

CONCLUSION

This research demonstrates the potential to develop innovative forms of support for people diagnosed with dementia while of working age. By building on the established field of career guidance, we co-produced and field-tested the Guidance for Life, Work and Career approach. Field testing revealed it could be an important tool to enhance both employment experiences and overall wellbeing for people living with dementia. Importantly, the findings challenge the notion that a dementia diagnosis should limit access to broader support services. Instead, career guidance offers a fresh and empowering perspective on how to support people with dementia in navigating work and life transitions.

RECOMMENDATIONS

- People with dementia should be enabled to make employment-related decisions post diagnosis, whether that is to continue work, explore alternative options or plan for post-retirement activities.
- Support services, including occupational health and employers should recognise the individual beyond their dementia diagnosis, respecting their skills, preferences, and choices.
- There is an urgent need to raise awareness to challenge public misconceptions and reduce stigma around the contribution people with dementia make to society and the workplace.
- More research is needed to understand how this research could potentially support people who are self-employed, particularly those who do not have formal or informal support mechanisms from organisations, or colleagues, post-diagnosis.
- The term career may not resonate with everyone. There is a need to consider the language and branding to make support feel accessible for people with dementia.
- Career guidance should be considered as part of post-diagnostic support plans for people diagnosed with dementia who may benefit.
- Talking to a trained professional, like a career professional, without clinical dementia knowledge may offer a different perspective on life, work and career post diagnosis.

ACADEMIC TEAM

- Professor Louise Ritchie, University of the West of Scotland (Principal Investigator)
- Dr Laura Lebec, University of the West of Scotland
- Professor Valerie Egde, Northumbria University
- Professor Debbie Tolson, University of the West of Scotland
- Dr Emma Bolger, University of the West of Scotland
- Professor Jill Stavert, Edinburgh Napier University
- Professor Katie Brittain, Newcastle University
- Dr Lucy Szablewska, Northumbria University
- Connor McDonald, University of the West of Scotland

CO-RESEARCHERS

- Stuart Dougall
- Kenny Moffat
- Rynagh Flynn
- Margaret McCallion
- Margaret Northedge
- Barry Northedge

PROJECT PARTNERS

- Skills Development Scotland
- Alzheimer Scotland
- Scottish Dementia Working Group
- National Dementia Carers Action Network

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