



WORKING WITH DEMENTIA

Information
for employees
with dementia

This guide has been prepared as part of a dissemination grant awarded by the Alzheimer's Society. It is based on the findings of the Alzheimer's Society funded project 'Dementia in the Workplace: the potential for continued employment post diagnosis' which was completed in 2015 and the Carnegie Trust for the Universities of Scotland funded project 'Employers' responses to Dementia in the Workplace in Scotland' completed in 2018.



Key facts about dementia

- Dementia is an umbrella term which describes a range of symptoms which progressively affect cognitive functioning.
- Alzheimer's disease is the most common cause of dementia, but there are a number of different causes of dementia.
- Although more commonly associated with older age, dementia can affect people of all ages.
- Symptoms of dementia include problems with a range of cognitive functions including:
 - / memory problems
 - / spatial awareness
 - / language and communication
 - / judgement and decision making
 - / changes in mood or personality



Dementia in the workplace

People with dementia often report they first notice symptoms in their employment. Problems remembering instructions which are not written down.

For an individual who is diagnosed with dementia whilst still employed, these symptoms can impact on their performance at work. However, it is possible for people with dementia to continue working after diagnosis, with the appropriate support.

Disclosing a diagnosis of dementia

- In order to access support with employment, employers need to be informed of the diagnosis. This can be a difficult conversation to have with an employer. Dementia is considered a disability under the Equality Act 2010, which requires employers to make reasonable adjustments to support employees and to help to retain employment. People with dementia in our study found the following helpful in disclosing their diagnosis to their employer.
- Having support from a family member, colleague or trade union representative.
- Disclosing diagnosis in a way you feel comfortable with, face to face, through email etc.
- Have a desired outcome from the meeting, for example, a referral to occupational health, specific forms of support.

Discussing support needs

It is important that employers understand dementia, and the effect it can have on an employee. Our research shows that many employers have a basic awareness of what dementia is but not how it could affect someone in employment. Having an open and honest conversation about your employment, your strengths and weaknesses in your role and the support you require is important to maintain employment. Dementia awareness training for colleagues and managers was helpful for people in the research as it helped colleagues and managers understand the effect dementia had on their co-worker and how best to support them. Other useful supports for people with dementia were:

- Adjustments to their job description
- Changes to working hours
- Flexible working and/or working from home
- Changes to the work environment, for example providing a quiet space free from background noise
- Using technology, mobile phones, online calendars etc
- Support and advice from family, friends and healthcare professionals



Person with dementia

“Taking some of the stress out of the job, knowing that other people are there if I get stuck, whether it’s the boss or work colleagues. This all helps me work.”

Leaving employment

Many people within our study spoke of their decision to leave employment. For some, this was soon after their diagnosis, while others made the decision after they had continued to work for a period of months and years. However, many people felt leaving work was difficult and they would have appreciated more support at this point. Examples of this were having a lack of support when completing the paperwork to apply for early retirement and no acknowledgement when they eventually left work. It is important to continue to have open conversations with employers throughout this process, in addition occupational health may be able to provide further support.



Person with dementia

"The early retirement form is a 24 page document. It's like filling in a job application for me, my line manager, occupational health, my GP...for everybody. It's a very in-depth form and my line manager actually said 'can we fill this in together because it is massive'."

Further support and information

Alzheimer's Society

www.alzheimers.org.uk/

National Dementia Helpline

0300 222 11 22

Alzheimer Scotland

www.alzscot.org

0808 808 3000

Age Scotland Early Stage Dementia Team

www.ageuk.org.uk/scotland/

0800 12 44 222

Dementia UK

www.dementiauk.org/

0800 888 6678

Young Dementia UK

www.youngdementiauk.org/

01993 776295 - general enquiries

01865 794311 - support-related enquiries

Dementia Friends

www.dementiafriends.org.uk/

www.dementiafriendsscotland.org/

Healthy Working Lives (Scotland)

www.healthyworkinglives.scot/Pages/default.aspx

Health at Work Network (NHS England)

www.nhshealthatwork.co.uk/

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