



Centre for
Dementia



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Working Age Dementia

Identification, Support and Management

Professor Amanda Griffiths

Division of Psychiatry & Applied Psychology, School of Medicine

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Outline

- Facts about working age dementia
- What does the scientific literature tell us?
- What do employers tell us?
- What can be done to support employees?
- On-line resources
- Discussion – your experiences



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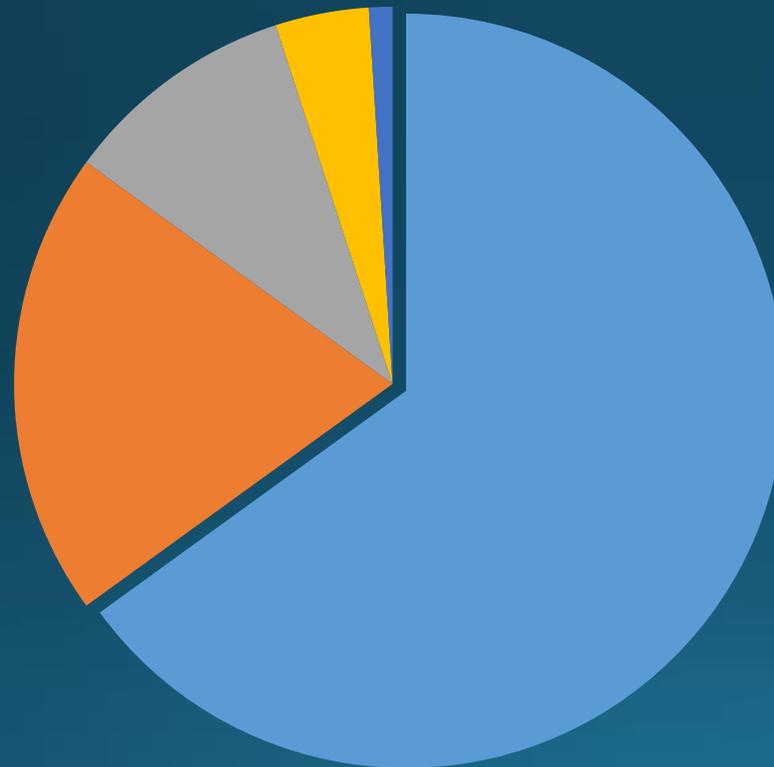
Facts



Working Age Dementia? WAD

- Working age dementia – people who develop dementia while still in employment
- Estimated - people of all ages living with dementia in the UK
 - 850,000 - rising to 1 million by 2025
<https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk/>
<https://www.nature.com/articles/ncomms11398>
 - 5% (42,000) of working age
- WAD – underestimate/rising numbers
 - large proportion of cases probably undiagnosed
 - more people working post-65
 - incidence of dementia doubles every 5 years between 65-90
<https://www.ncbi.nlm.nih.gov/pubmed/9748017>

Forms of Dementia



Type

- Alzheimers 65%
- Vascular 20%
- Lewy bodies 10%
- FTD 4%
- Rarer forms 1%

Working Age Dementia (WAD)



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Type

- Alzheimers 30%
- Vascular 20%
- FTD 13%
- Alcohol rel 10%
- Lewy bodies 5%
- Rarer forms 22%

Symptoms



Alzheimer's

- ability to remember recent events, conversations
- getting lost in familiar surroundings
- difficulty recalling names and words

FTD behavioural (60%)

- losing inhibitions, interest in people/ things, empathy/sympathy
- craving sweet/fatty foods
- struggling with planning/finances

FTD progressive non-fluent aphasia

- slow, hesitant speech, grammatical errors, problems with complex sentences

FTD semantic

- problems with the meaning of words, finding right word, recognising people/things

Symptoms 2



Vascular

- difficulty concentrating, planning, organising
- low mood
- slower speed of thought

Alcohol related & Korsakoff's syndrome

- Varies depending on part of brain affected
- Poor planning, impulsivity, poor attention, slower reasoning, lack of sensitivity, empathy, sympathy

Dementia with Lewy bodies

- Fluctuating alertness
- Visual & auditory hallucinations
- Disrupted sleep & sense of smell, depression

Creutzfeldt-Jacob, Huntington's, Parkinson's, HIV related and others

- Varies depending on part of brain affected



Why is Diagnosis Difficult?

- Assumption – “dementia is an older persons condition”
- Rarer dementias in younger people - less well understood
- Symptoms might not include loss of memory or confusion
- Symptoms might suggest other health problems
- Cognitive tests developed for some types of dementia may be misleading for others
- People may leave work before diagnosis & support

The Wider Perspective - Family



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- Wife, carer, breadwinner, mother, referee, advocate?
- Maintaining a family income
- Considering the needs of children
- Genetics & wider family support
- Need for joined up services & functions: eg:
 - NHS, social services, carers' networks, dementia charities, employers, HR, occupational health



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Scientific Literature

Study 1

Literature Review



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- Funded by Public Health England
- 8 databases & dementia journals websites
- Q - the management of employees who develop dementia whilst in employment?
- 22 journal papers, 1 PhD thesis, 21 web articles
- 3 themes - presentation & identification at work, reasonable adjustments, provision of information

Thomson L, Stanyon M, Denning T, Heron R, Griffiths A. (2019) Managing employees with dementia: a systematic review. *Occupational Medicine*

<https://academic.oup.com/occmed/article-abstract/69/2/89/5203832?redirectedFrom=fulltext>



Presentation at Work

- Concealing difficulties, restricting activities, self-manage
- Fear reactions of managers & co-workers, discrimination if seeking a new job
- Symptoms at work related to changes in behaviour, and to cognitive skills & performance, eg:
 - aggression (mostly verbal), irritability, apathy, reluctance to engage with others, depression & anxiety, loss of confidence
 - not performing to previous standards – concentration, numerical ability, dealing with the abstract, repetitions during conversations, missed appointments, misplacing things



Pathways to Diagnosis

- Reluctance to discuss concerns with employers (flagging a potential health issue) may contribute to dismissal on performance grounds
- Examples of good support but much evidence of harsh treatment of employees & traumatic cessation of employment
- Advice available for employers in approaching the topic sensitively & how to be supportive
- Time from acknowledgement of symptoms to diagnosis
- Employees report diagnosis is helpful



Remaining in Work

- Shock associated with loss of planned future and prospective loss of employment
- Many desire to stay in work as long as possible –
 - purposeful activity & self-esteem
 - independence
 - negative impact of job loss on families & relationships
 - financial hardship
- Important role for employers being flexible & providing reasonable adjustments to work



Reasonable Adjustments

- Process of deciding on adjustments should be collaborative
- Advice available on websites
 - establish routines
 - clear signage and labelling
 - quiet spaces
 - use of smart devices for reminders
 - home working, flexible working, redeployment, reduced hours
 - review health & safety risks to self & others
 - involve co-workers where possible

Alzheimer's Society (UK)

Australian Government Job Access

Alzheimer's Australia

DEEP (UK)

Dementia Engagement & Empowerment Project (DEEP)



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- DEEP supports groups of people with dementia in the UK to try to change services & policies that affect the lives of people with dementia <https://www.dementivoices.org.uk/>
- Including guides for organisations wanting to work well with people who have dementia – eg.
 - tips for employers who want to be more dementia friendly <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Tips-for-employers.pdf>
 - writing dementia-friendly information <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf>



DEEP – Points for Employers

- Ensure employees with dementia knows their experience & skills are valued
- Be honest regarding concerns & reasonable adjustments to the job – carry out risk assessments
- Recruit local expert help – occupational health or dementia groups – to support employees
- Encourage open dialogue & review regularly



What do Employers do?

- Some examples of good employer support, but also ...
- Frequent reports of no (or inadequate) adjustments
- Little will to acknowledge remaining skills or redeploy
- Employees dismissed – some before diagnosis & before adjustments could be considered
- Low paid/manual workers more likely to face quick dismissal
- Often missing - reaching an agreement with employees about a dignified exit



Information Needed

- Employers - to raise awareness in the workplace
- Employers – to understand that employees can continue to work
- Employers - recognise dementia as an illness and reason for early retirement so as to maintain pension rights & other benefits
- Employers - could be a focal point for dissemination of information
- Health professionals – more awareness of WAD & employment law
- **Employees** - access to information about early retirement, redundancy, employment pensions & state benefits



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What do Employers Need to Know?

Study 2



Interviews

- UK employers, employers bodies, unions, charities, occupational health
- Three major themes identified:
 - nature & extent of the challenge
 - awareness & skills
 - policy & practice

publication in preparation



Support for Carers

- Raised by many of our participants
- One in nine workers are carers <https://www.carersuk.org/>
- One in five carers give up work - to care full-time
- Flexible work schedules help
- Flexible working can mean:
 - part-time, flexi-time, job sharing, staggered hours, compressed hours, annualised hours, working from home, phased retirement, etc
- 'Employers for Carers' <https://www.employersforcarers.org/>



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Resources



Lived Experience

- Wendy Mitchell (2018). *Somebody I used to know*. London: Bloomsbury.
- Book -diagnosed with dementia aged 58 – describes over the years the impact on herself, her career, her family
<https://www.bloomsbury.com/uk/somebody-i-used-to-know-9781408893340/>
- Blog 'Which me am I today?' <https://whichmeamitoday.wordpress.com/>
- "People like me still have a substantial contribution to make; we still have a sense of humour; we still have feelings.... Living as well as you can with dementia is all about adapting...to new ways to enable us to live better, for longer, with dementia."



Resources 1

- DEEP - Dementia Engagement and Empowerment Project
<https://www.dementiavoices.org.uk/>
- Alzheimer's Society <https://www.alzheimers.org.uk>
- Alzheimer's Society – Creating a Dementia-Friendly Workplace (2015)
<https://www.alzheimers.org.uk/get-support/publications-factsheets/creating-dementia-friendly-workplace> *(includes information about other resources)*
- Dementia UK <https://www.dementiauk.org/>
- Centre for Ageing Better (2018) Becoming an age-friendly employer
<https://www.ageing-better.org.uk/sites/default/files/2018-09/Being-age-friendly-employer-evidence-report.pdf>
- The Many Faces of Dementia – free, on-line course from UCL (useful for understanding less common forms of dementia)
<https://www.futurelearn.com/courses/faces-of-dementia>



Resources 2

- ACAS * – The Equality Act – What’s new for Employers? (2011)
- ACAS - Dealing with Dementia in the Workplace
<http://www.acas.org.uk/index.aspx?articleid=5429>
- Carers’ Trust East Midlands
<https://www.carerstrustem.org/useful-information>
- Dementia Friends (UK)
<https://www.dementiafriends.org.uk/WEBArticle?page=about-partner-organisations#.XBjwOZBLE5s>
- Employer Responses to Dementia in the Workplace in Scotland
<http://nrl.northumbria.ac.uk/37147/>

*Advisory, Conciliation & Arbitration Service

Thank you



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amanda.griffiths@nottingham.ac.uk