



# Dementia Symptoms While in Paid Employment: Impact on Occupational Competence and Occupational Participation

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# Background

Government policy is shifting to increase workforce participation of 'older workers'. Therefore, the number of individuals presenting with signs and symptoms of a dementia whilst still in paid work is also likely to increase

Alzheimer's Society UK, 2014, Silverstein 2008, Australian Government, 2013, Australian Law Reform Commission, 2012, Department for Work and Pensions, UK, 2011, Employment, Labor and Social Affairs Committee 2015, Productivity Commission, 2013, Renehan et al., 2012, Ritchie, et al, 2017, The Organization for Economic Co-operation and Development, 2015).

# What we know:

1. Dementia is NOT A NATURAL PART of ageing
2. Dementia is not ONLY a disease of older age
3. Onset of symptoms are hard to define
4. Over time, disease progression impacts on capacity to perform activities of daily living, including paid work.

(Andrew et al 2018; Brown et al. 2017; Chaplin & Davidson, 2016; Ritchie et al. 2017, WHO, 2019).

# We also know that:

Expert advice regarding reasonable workplace adjustment enables employers to manage occupational risk and extend workforce participation for workers with dementia

However, many employers feel ill-equipped to

- (i) recognize symptoms of cognitive decline in the workplace;
- (ii) and address problems and issues when a worker is experiencing onset of a dementia. (Roach et al., 2008, Steeman et al., 2006)

# Therefore,

Employers and their HR representatives requested:

- (i) organizational strategies for identifying and addressing changes in a worker's functional capacity possibly related to dementia,
- (ii) advice regarding provision of reasonable adjustment within the workplace; and
- (iii) ways to access to a supported transition to medical retirement

(Cox & Pardasani , 2013, Thomson, Stanyon, Dening, Heron & Griffiths, 2018).

# How confident are you about:

(i) recognizing a worker's symptoms of cognitive decline in the workplace



very



somewhat

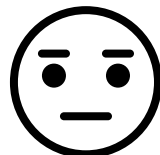


not at all

(ii) addressing problems and issues with a worker who is experiencing onset of a dementia



very



somewhat



not at all

# Overview

We will explore topics about the impact of dementia on workforce participation including:

- Who is 'the older worker' ?
- What is dementia and why are symptoms difficult to diagnose?
- How does dementia impact on workforce participation during the pre-diagnosis, diagnostic and post diagnosis phases of dementia?
- What policy and practice strategies can be applied to inform more favourable outcomes for both workers and the organisations they are employed by?

# Who is the older worker?

- Changes to mandatory retirement ages
- Incentives to keep people at work
- Inconsistencies in defining the age at which someone is deemed an 'older worker'

[\(https://www.ncbi.nlm.nih.gov/books/NBK207714/](https://www.ncbi.nlm.nih.gov/books/NBK207714/),

The Age Discrimination in Employment Act (ADEA), 29 U.S.C. 621 et seq.,

McCarthy, Heraty et al. 2014)



# ‘Older worker’ changes in functional capacity

## Changes in physical function

- changes in muscle strength, range of motion, cardio-vascular and respiratory fitness, balance, sleep patterns, heat regulation, vision and hearing (Nancy Parchana, 2017)

# 'Older worker' changes in functional capacity

## Changes in cognitive function

- Capacity for learning new tasks, multi-tasking and selective attention gradually declines with age.
- Verbal tasks (talking and expressing) remain constant or improve.
- Tasks that depend on short-term memory usually take longer.

[https://www.ccohs.ca/oshanswers/psychosocial/aging\\_workers.html](https://www.ccohs.ca/oshanswers/psychosocial/aging_workers.html)

# 'Older worker' changes in functional capacity

For example, a person may find it hard to:

- work with complex or confusing stimuli
- work in a busy environment where lots is going on
- focus attention only on information relevant to the task at hand especially in "new" situations.
- Prioritize what to pay attention to, and what to ignore.
- ([https://www.ccohs.ca/oshanswers/psychosocial/aging\\_workers.html](https://www.ccohs.ca/oshanswers/psychosocial/aging_workers.html))

# Megan

*'Megan was finding work more challenging. Things that used to be easy were becoming more frustrating. There were things about work that were still enjoyable, like the social aspects of meeting up at morning tea and lunch, but things like meeting targets and deadlines, keeping up with the computer side of things, that was getting harder.*

*It was time to take leave, semi-retire, maybe start a small part time business, or work as a seasonal fruit picker and travel.*

*However, within 6 months of leaving work after retiring a zero speed traffic accident in the Mall carpark became the crisis that led to medical investigation and eventually a diagnosis of dementia.*

*In hindsight, this explained those niggling things that were making work more difficult'* (Andrew et al, 2018)

# What is dementia?

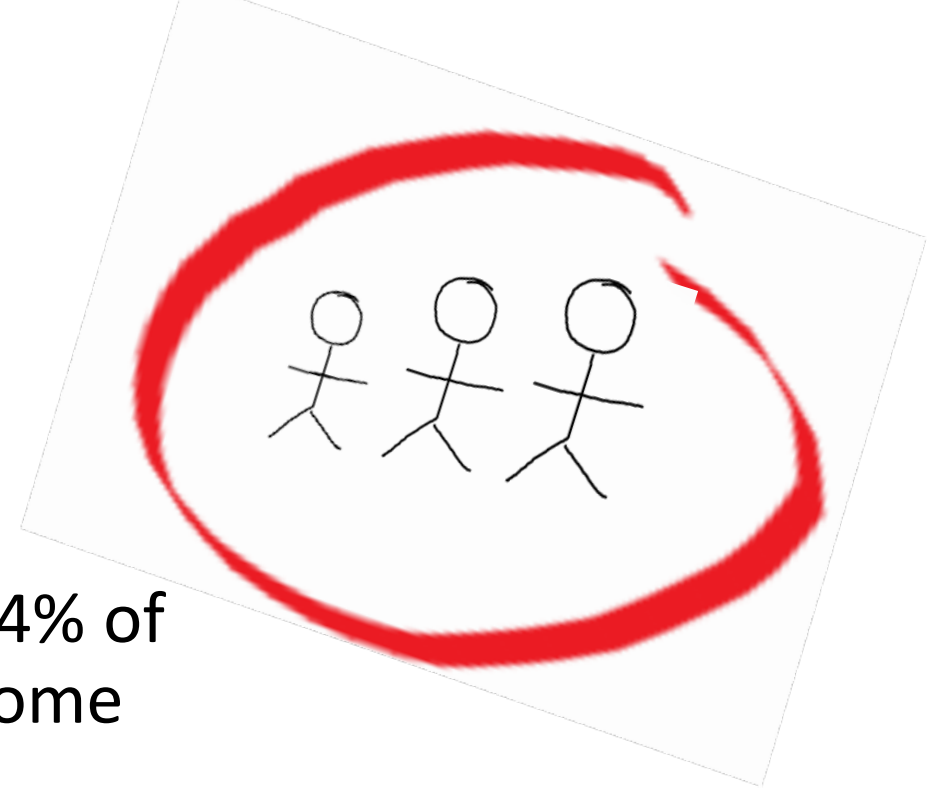
- Umbrella term describing a set of symptoms of cognitive decline that gradually impact on memory, thought processing and capacity to perform routine activities of daily living
- Most common types: Alzheimer's disease (AD), vascular dementia (VD) and Lewy-body dementia



(WHO, 2019)

# What is dementia?

- Dementia not only impacts older people
- Similar to other developed countries, approximately one in every 1000 people or 3.4% of the US population under the age of 65 have some form of dementia.
- 6% for 65 69 years
- 10% for 70 to 74 years



(<https://www.alz.org/media/documents/facts-and-figures-2018-r.pdf>)

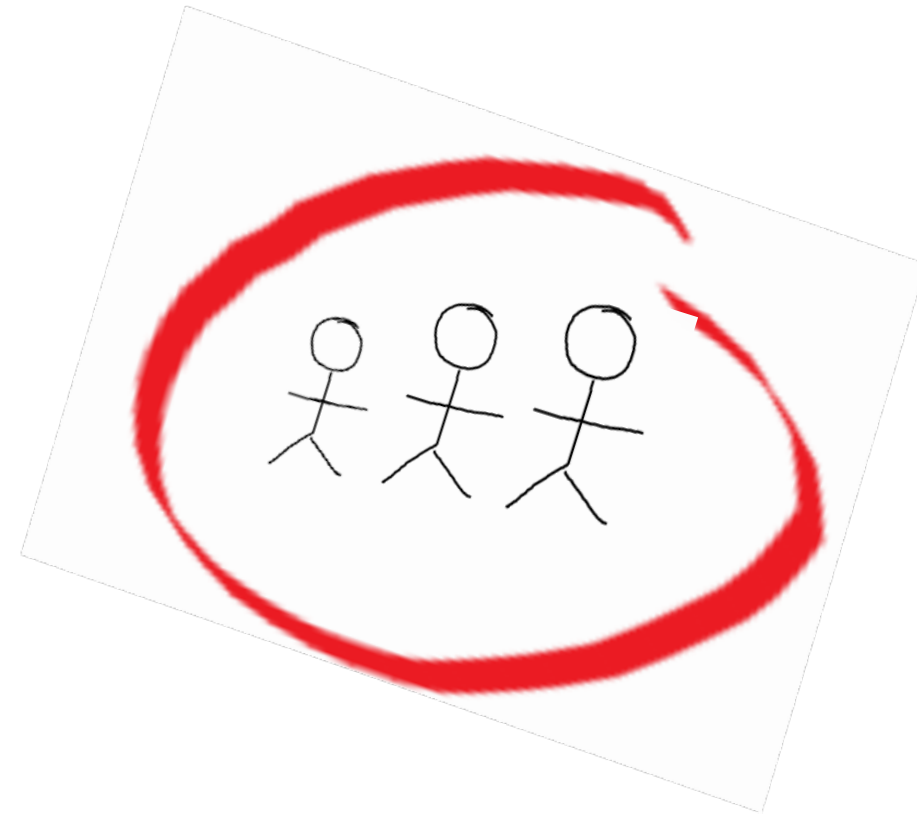
# What is dementia?

Dementia symptoms are:

- different to 'normal ageing'
- more specific

Range of deficits at work

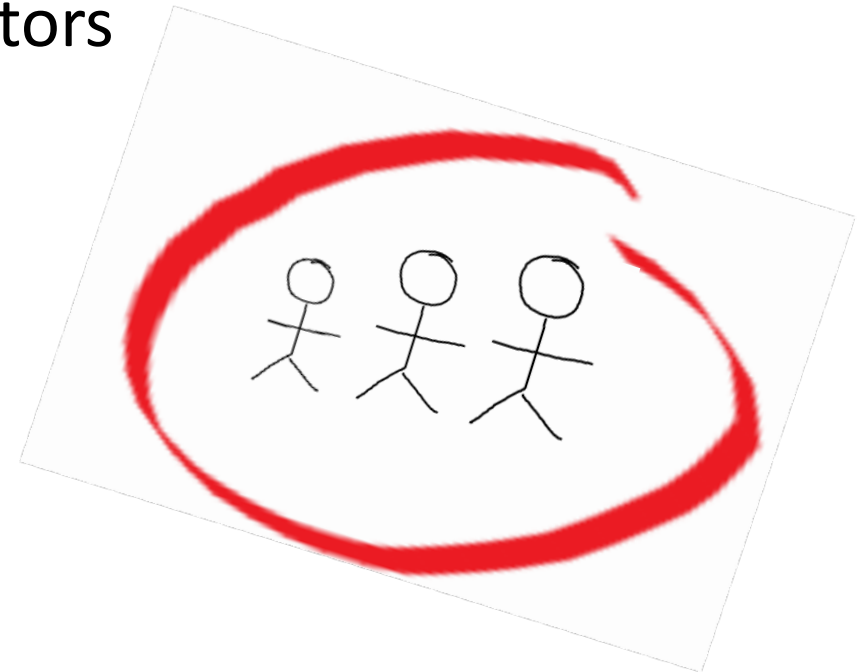
- problems with short term memory
- planning
- judgement and executive functioning, orientation to time and place
- recognizing people or objects.



(Chaplin & Davidson, 2016; Lurati, 2014; Öhman et al., 2001; Ritchie et al., 2017).

# Why is dementia difficult to diagnose?

- Time of onset can be hard to define
- Obtaining a timely diagnosis can be
- Symptoms are often misattributed to other factors e.g. stress, substance abuse, or normal ageing



(Chaplin & Davidson, 2016; Lurati, 2014; Öhman et al., 2001; Ritchie et al., 2017).



# Karen

*' I had been the area manager, in-charge of staff, budgets and portfolio's....And so when some of the things that were changing for me [at age 45], like some strange memory loss, not just short-term but some long-term. and this dyslexia thing, suddenly I couldn't spell "that" and was seeing numbers back to front. I didn't for one second expect to be told after two years of testing it was dementia' (Participant interview, 2017)*

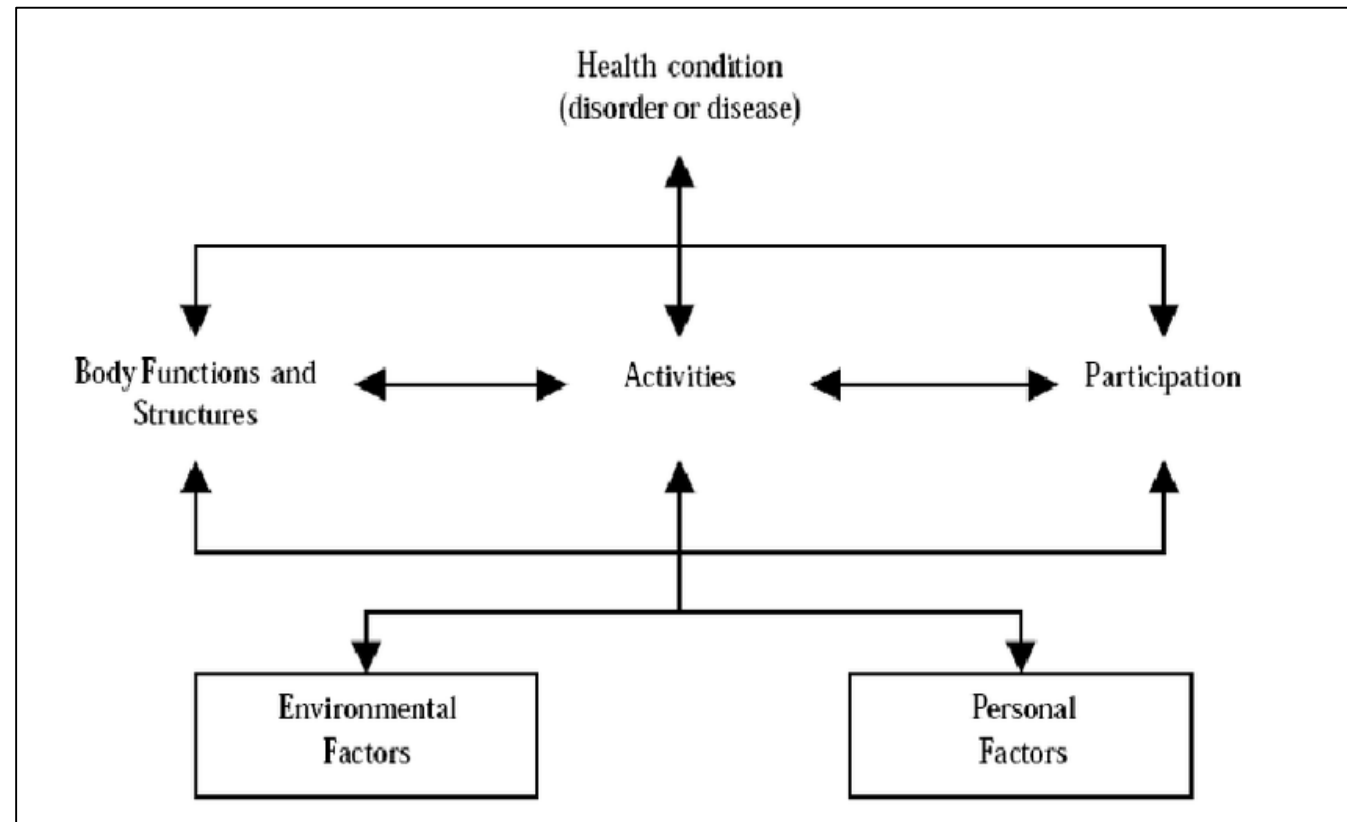
(Andrew, et al, 2018).

# Impact on work

The impact of dementia on capacity to carry out complex work tasks differs between individuals due to:

- type and progression of the disease; and
- variations in physical, cognitive and psycho-social demands across occupations

(Andrew, Phillipson & et al., 2018, Öhman et al., 2001))



ICF Model – WHO accessed 2018

# Therefore....

Understanding ways to identify and appropriately address potential onset and progression of symptoms in the workplace is important

(Harris & Keady, 2009; McCulloch et al. 2016; Cox & Pardisani; 2013; Ritchie, Tolson & Danson, 2017)

# Impact on workforce participation across 3 phases

- Prior to diagnosis
- During the diagnostic phase
- After diagnosis

(Steeman, et al, 2006)

# Pre-diagnosis phase

The workplace is often where changes in capacity to carry out habituated routines ' raises concerns amongst worker's, their supervisors and/or co-workers.

Change in capacity triggers a 'crisis' that may lead to either:

- seeking diagnosis; or
- terminating poorly performing workers who are later medically diagnosed with dementia.

(Andrew et al,2018, Chaplin & Davidson, 2016; Lurati, 2014; Öhman et al., 2001; Ritchie et al., 2017).

# Employers and co-workers may observe unexplained changes such as:

- increasingly slow in completing tasks
- being forgetful
- demonstrating lack of motivation
- making critical mistakes
- difficulty performing usual routines
- inability to learn new routines as quickly as peers

(Chaplin & Davidson, 2016; Lurati, 2014; Öhman et al., 2001, Ritchie et al., 2017)

# Ross

*'... I got called to a meeting with the management team. It was to be the first of 3 performance management meetings over the next 6 months. How could someone who loved work and had such a great reputation now be struggling to meet the deliverables? The boss put it down to stress, non-work related of course. I was banned from working extra long hours. It got down to the last and final warning. Then one afternoon I lost the work car after parking it in a familiar location to do a site visit. It was very scary. I was very late back to the office'* (adapted from participant interview, 2017)

(Andrew et al, 2019)

# Hypothetical Q's - if you were the boss:

- (i) What assumption might you have made as to the cause of changes in work behavior?
  - a) Non-work related stress, family pressure
  - b) Typical problems of an older worker
  - c) Might be a medical reason such as brain tumor or dementia
  - d) Effects of drinking heavily
  
- (i) How might you have addressed the changes in Ross's work behavior?
  - a) Initiate the termination process via HR
  - b) Raise concerns with Ross and initiate medical investigation
  - c) Make contact with Ross's wife to express concerns
  - d) Start surveillance



# During the diagnostic phase

Difficulty coping with work can become a catalyst for seeking a medical diagnosis to explain changes in performance.

(Andrew, et al, 2018, Lurati, 2014, Öhman et al., 2001)

# Ross

*'.....So after the final warning, I knew something was not right. I didn't go back to work. I took sick leave. I was just naughty because I wasn't getting the work done. A friend of a friend fast tracked an appointment with a neuro specialist and after a series of tests I was diagnosed with probable dementia. It was not the diagnosis I expected. The attitude of the HR person changed immediately. There was genuine concern. She helped me file for medical retirement. Even if they had offered me support to stay, I couldn't go back, I was a wreck by then. At least with medical retirement, financially we could survive'*

*(adapted from participant interview, 2017)*

# Post diagnosis phase

That explains everything!

The impact of dementia on the transition from work to retirement was influenced by opportunities to :

- (a) work with 'reasonable adjustment'
- (b) plan for the timing of retirement.

(Andrew, et al 2018, Chaplin & Davidson 2016, Harris & Keady, 2009, Lurati, 2014, Ritchie et al., 2017)

# Two scenarios, two outcomes

Karen

*'After I was diagnosed, nothing really changed until I lost my driver's license. I was asked to leave. Terminated. No medical retirement, no farewell. And it is obvious, I could still be doing a telephone sales position. I was doing a regional sales manager's job and obviously needed to drive. Had I realized, or my doctors or Alzheimer's [Association] told me about my disability rights, I should never have been asked to leave.'*



Pete

*'I told my employer once I was diagnosed. I was offered reasonable adjustment and reduced hours. The company was extremely supportive.'*

*When the time came to medically retire there will be a big send off'*



*(adapted from participant interviews, 2017)*

# Key enablers for supporting a worker diagnosed with a dementia

- (i) Initiate important conversations with the worker and understand their preferences about staying at work or ceasing

It is important that employees are given opportunity to share a diagnosis with their employer without fear of dismissal

# Key enablers for supporting a worker diagnosed with a dementia

(ii) Engage with stakeholders early, including health professionals, HR, OHS and others to inform decisions about staying at work or ceasing

This enables informed discussion about whether to stay at work for as long as possible, and access medical retirement

# Key enablers for supporting a worker diagnosed with a dementia

(iii) Seek expert advice regarding reasonable adjustments recommended to continue safe and productive workforce participation

People living with dementia can extend their paid worker role with access to reasonable adjustment including modification of duties and hours of work

Rhetorical question: What do you see as the main barrier to providing reasonable adjustment in your work place?

# Key enablers for supporting a worker diagnosed with a dementia

(iv) Stage the transition from a full-time role as symptoms progress

And when the time comes to cease work, provide opportunity for the worker to accept recognition of 'job well done' and say goodbye, or leave quietly



# Re-writing Karen's story

Karen

*After I was diagnosed, nothing really changed until I lost my driver's license. I was asked to leave. Terminated. No medical retirement, no farewell. And it is obvious, I could still be doing a telephone sales position. I was doing a regional sales manager's job and obviously needed to drive. Had I realized, or my doctors or Alzheimer's [Association] told me about my disability rights, I should never have been asked to leave.*

What if:

Karen and her manager discussed the impact of the diagnosis on her work roles.

Employer referred to HR who sought expert advice from Karen's Dr and the RTW coordinator

Help was sought with matching and re-matching work tasks with Karen's abilities

Reasonable adjustments were put in place

Plans for medical retirement was discussed and put in place

Karen had a chance to farewell her colleagues

(Andrew et al, 2018)

# Recommendations

- Adopt workplace initiatives to increase awareness about the impact of early symptoms of an unexplained decline in work performance
- Provide opportunities to support workers as they 'transition to retirement to encourage disclosure without fear of termination
- Access suitably qualified experts to assist with determining the extent to which changes in functional capacity may or may not impact on an individual's capacity to undertake critical work demands
- Support worker decline in functional capacity through provision of reasonable workplace adjustment in line with disability discrimination law are also required

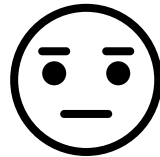
(Andrew, et al, 2018, Cox & Pardisani, 2013; Ritchie et al, 2015; Ritchie et al, 2017).

# How much has your confidence level changed about:

(i) Recognizing a worker's symptoms of cognitive decline in the workplace



very



somewhat



not at all

(ii) addressing problems and issues with a worker who is experiencing onset of a dementia



very



somewhat



not at all

# Conclusion

- i. WHS implications for onset of cognitive decline associated with policy and practice strategies to extend workforce participation for older workers need to be addressed.
- ii. Increased awareness of how changes in work performance may be related to symptoms of undiagnosed dementia or other types of cognitive decline is needed in order to support the worker, co-workers and employers.
- iii. Workplace policy and practices that align with worker rights and employer responsibilities for reasonable adjustment and medical retirement is required to support those presenting with symptoms of dementia at work.



**Southern Cross  
University**

Time for questions

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