

Dementia

Professor Dawn Brooker

University of Worcester
Association for Dementia Studies


Dementia Care Awards 2019
WINNER

THE AWARDS 2019
WINNER
Researching Dementia in the Local Community

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Association for Dementia Studies (est. 2009)

Developing evidence-based practical ways to help people live well with dementia




- Multi-professional innovative research centre
- Inclusive of people directly affected by dementia
- Education and practice development.
- Postgraduate Distance Learning
- PhD studentships
- Expertise in person-centredness, families, communities, arts, sport, nature, design, technology, complex care from pre diagnosis to end of life.

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Understanding about dementia



- You probably know more than you think
- Utilise a series of True/False questions to help us discuss some of the common areas you need to know about for practice

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True or False?

Dementia is an “umbrella term” for diseases that cause progressive, non reversible damage to the brain. There are over 200 types of dementia, each describing a different way in which the death to the brain cells occur



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True or False?

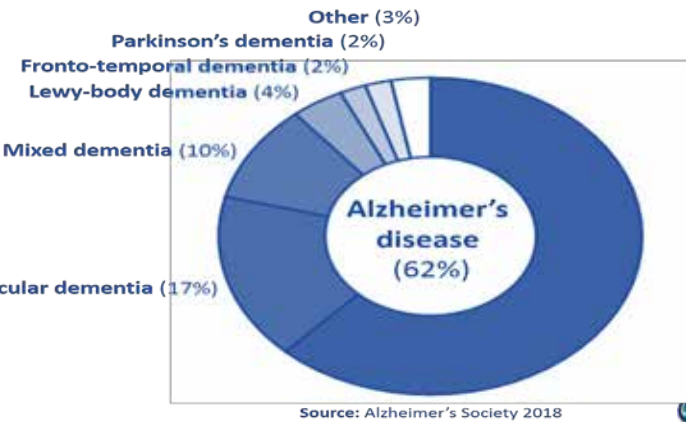
Alzheimer's disease is the most common type of dementia

TRUE

Followed by.... Vascular dementia, Mixed dementia, Dementia with Lewy bodies, and Fronto-temporal dementia



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Good short animation on understanding the aetiology of common dementia sub types

Alzheimer's Research UK film:

<https://www.youtube.com/watch?v=HobxLbPhrMc>



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True or False?

There are an estimated 860,000 people in the UK living with dementia

TRUE

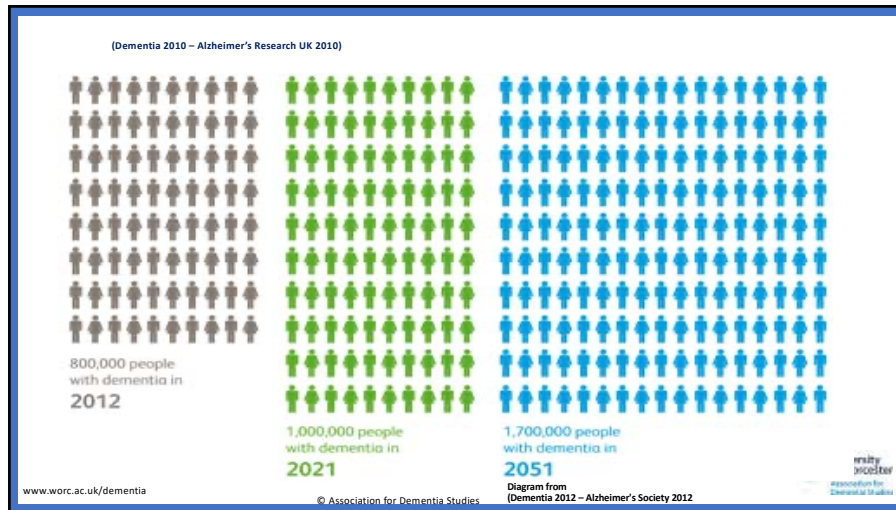
By 2050 it will be..... 1.7 million

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Really big numbers.... global

- Numbers with dementia expected to double every 20 years
- 24 million now to 81 million by 2040
- By 2040, 71% of people with dementia will live in low and middle income countries
- Dementia is a global issue

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True or False?

Once over the age of 60, your risk of developing dementia doubles every 5 years

TRUE

60 – 1% 65 – 2% 70 – 4% 75 – 8%
80 – 16% 85 – 32%

Alzheimer's Society, 2014



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Worcestershire: Estimated age breakdown of citizens living with dementia

Age group	2006	2011	2026
30-64	200	200	200
65-69	300	400	400
70-74	600	700	900
75-79	1,100	1,200	2,000
80-84	1,700	1,800	3,000
85-plus	2,900	3,700	6,600
Totals	6,900	8,000	13,100

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True or False?

The first symptom of dementia is memory loss

False

Poor learning of new information is a common symptom, particularly in Alzheimer's disease there are many other symptoms, and for some types of dementia other symptoms might show first.

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Understand the disability

Making sense of my surroundings and my relationship to it

Parietal Lobe

Frontal Lobe

Reasoning, social behaviour, stopping & starting

Occipital Lobe

Making sense of visual perception

Memory, speech & understanding

Temporal Lobe

Cerebellum

Brain Stem



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Dementia Cognitive symptom awareness:

Both site and degree of damage will determine symptom pattern

- Memory (Disorientation & amnesia)
 - difficulty learning & remembering recent things
- Communication (Dysphasias)
 - difficulty understanding and using language
- Body awareness (Dyspraxias)
 - difficulty doing practical tasks
- Visual processing (Agnosias)
 - difficulty with visual perception
- Planning, judging and controlling (Dysexecutive function & Disinhibition)
 - difficulty planning & controlling behaviour

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The Alzheimer time-line

First in – last out

Early years

Middle years

Later years

Since dementia set in

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What does it feel like?

- Emotional reactions are as strong as ever
- Past events & memories feel much more present than recent ones
- Present events will trigger past memories
- What is happening in the present moment has a significant impact on how the person feels



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When you have met one person with dementia.....

- What might feel like if I had dementia?
- What would I want from those around me?
- What would other people see me doing?
- What wouldn't I want from those around me?



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Life-story: Remember who I am, what I love, what scares me



- Recalling the past plays to the person's strengths
- Enjoyable shared activity for family members
- Objects, photos, music and dance stimulate memories
- Maintains *a sense of identity*
- New people understand the person with dementia better if they know their life-story
- What's in your memory box? What are your treasures for the journey?



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Approaches to support memory strengths



- a relaxed atmosphere supports memory recall
- reduce questions that test short term memory
- use prompts and cues to aid recall
- repetition really helps
- procedural memory helps people with dementia learn new processes
- importance of emotional memories



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Approaches to support visual perception

- Use objects that look like a typical example: e.g cups, toilets
- Use high contrast to make objects stand out
- Be aware of shadows and lighting that may be misinterpreted
- Make sure items are within line of sight
- Use touch and sound to give extra cues

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True or False?

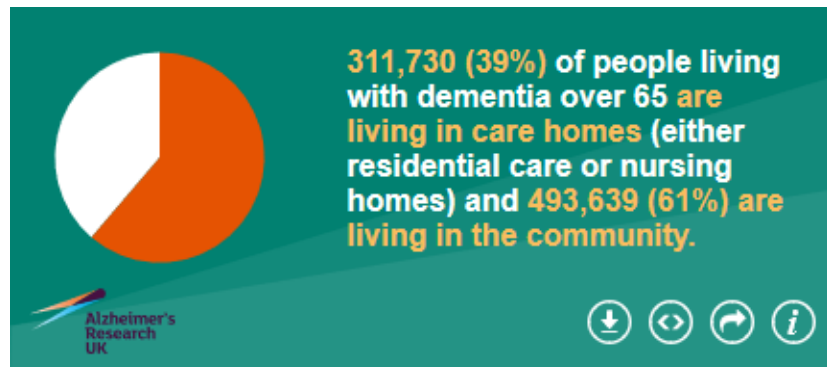
60% of people aged over 65 with dementia live in care homes.

False

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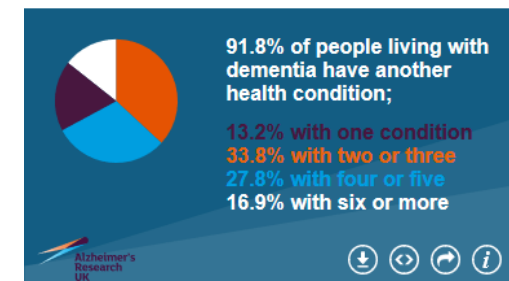


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True or False?

50% of people living with dementia have another health condition in addition to their dementia

False




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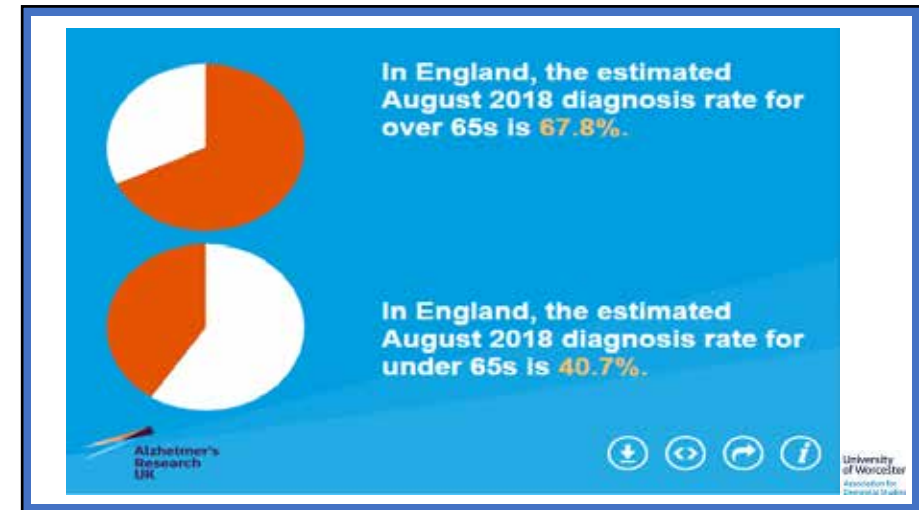
True or False?

80% of those 850,000 living with dementia have a diagnosis.

False




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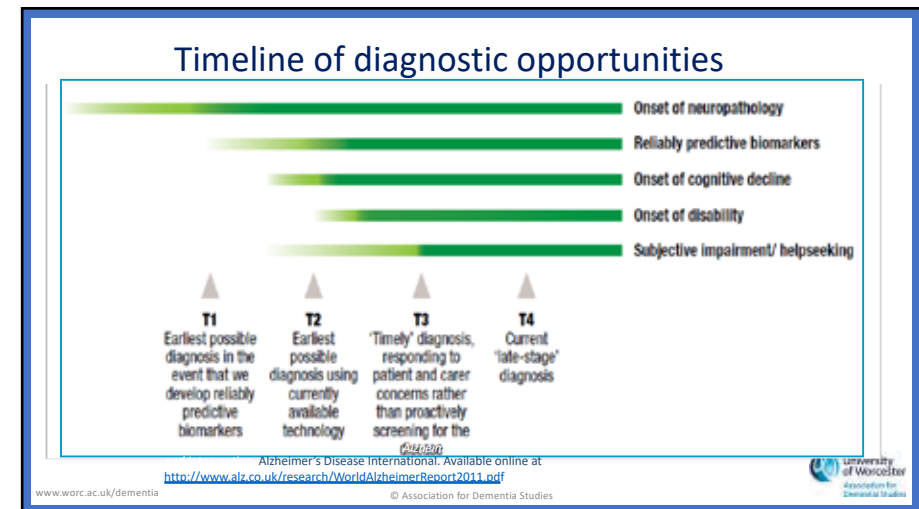
The Numbers Around Diagnosis

- Diagnosis rates in 2012 – 42%
- Diagnosis rates in 2015 – 61.6% (the target was 66%)
- Diagnosis rates in 2017- 68%



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Benefits and Risks of shifting diagnosis from T4 to T3

	Benefit	Risks
Person living with dementia	The right to know Time to adjust and plan Ability to make decisions including advanced care planning Improved quality of life Access to treatment, intervention and services	Negative attitudes towards the person diagnosed Misdiagnosis because earlier presentation more complex Hopelessness, Depression, Fear, Anxiety
Family	Understanding the changes Time to adjust Opportunity to build support. Access to services	Negative attitudes towards people Changing dynamics in families can overwhelm or increase risk of "abuse" Isolation, loneliness, fear, despair
Health and social care economy	Social and fiscal benefits Support services for family carers	No services available or services are targeted at later stage. Without services to help those diagnosed the benefits to people and their families will be lost

Nuffield council on Bioethics, 2009; Banerjee & Wittenberg, 2009; Prince et al, 2011; Weimar & Sager, 2009; Bamford, 2011; Brooker et al., 2014

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True or False?

People living with dementia lack mental capacity to make decisions about health treatments.

False

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Mental Capacity and Dementia

- A diagnosis of dementia is a reason to question whether someone might have a problem with decision making capacity.
- People's rights are protected under the Mental Capacity Act.
- Decision making capacity is situation and time specific.
- Can the person
 - understand the information that is relevant to the decision they want to make
 - retain the information long enough to be able to make the decision
 - weigh up the information available to make the decision
 - communicate their decision

Best Interest Decisions are made ONLY if a person lacks capacity
Lasting Power of Attorney for Finance, Health and Welfare

Advance Decision Making

<https://www.alzheimers.org.uk/get-support/legal-financial/decision-making-and-mental-capacity>

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NICE Dementia Guideline 2018

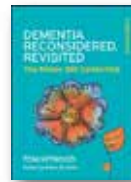
<https://www.nice.org.uk/guidance/ng97>



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NICE Guideline on Dementia 2018 Person-centred care (and 2006)



- Human **V**alue the person and their families and carers (regardless of age or cognitive impairment)
- **I**ndividuality of people living with dementia and how their personality and life experience influence their response to dementia
- Understands the importance of the **P**erspective of the person with dementia
- Relationships and interactions with others (**S**ocial environment) promotes well-being.



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Person centred: Care fit for VIPS

V = Values people
I = Individuals needs
P = Perspective of service user
S = Supportive social psychology

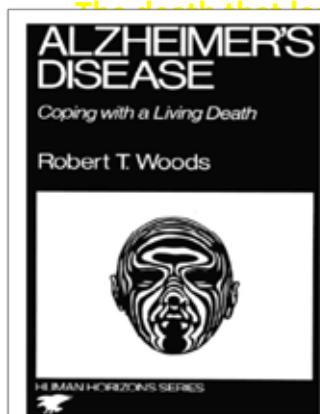
Brooker, D. (2004) What is Person Centred Care for people with dementia? *Reviews in Clinical Gerontology* 13 (3). 215-222.

Brooker, D. (2007) *Person Centred Dementia Care: Making services better* London, Jessica Kingsley Publications

Brooker, D. & Latham, I. (2016) *Person Centred Dementia Care (2nd Edition)* London, Jessica Kingsley Publications



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Woods, 1999, p.35



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Being a Person-Centred Practitioner

- Do my actions show that I respect, **value**, and honour this person?
- Am I treating this person as a unique **individual**?
- Am I making a serious attempt to see my actions from the **perspective** of the person I am trying to help? How might my actions be interpreted by them?
- Do my actions help this person to feel **socially** confident and that they are not alone?



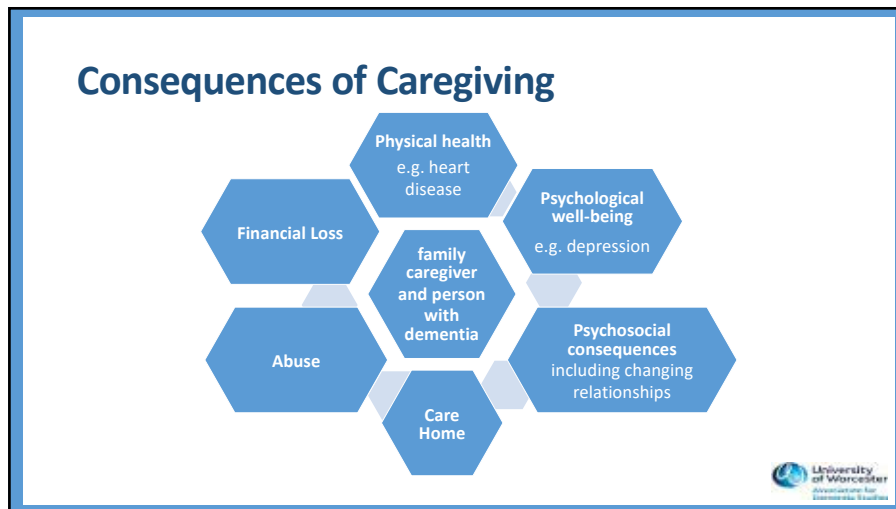
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www.carefitforvips.co.uk

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Post diagnosis

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Review after diagnosis

- After a person is diagnosed with dementia, ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service.
- Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.

Thanks to Dr Richard Clibbens South Yorkshire NHS for this slide.

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Interventions to promote cognition, independence and wellbeing

- Offer a range of activities to promote wellbeing that are tailored to the person's preferences.
- Offer group cognitive stimulation therapy to people living with mild to moderate dementia.
- Consider group reminiscence therapy for people living with mild to moderate dementia.
- Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.

Thanks to Dr Richard Clibbens South Yorkshire NHS for this slide



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Study with us on-line to gain a qualification in person-centred dementia care

Post-graduate modules and qualification in Leading dementia care; Expert practice; Advanced dementia; Family care; Design and environments; Engagement and empowerment.

Fully on-line, interactive, evidence based created and delivered by experts in their fields
Part-time study to fit in with commitments

Closing date for September 2020 intake is 20th July 2020

<https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-education-and-research/ads-university-courses.aspx>

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Further reading

- Brooker, D., La Fontaine, J., Evans, S., Bray, J. & Saad, K., (2014) Public health guidance to facilitate timely diagnosis of dementia: Alzheimer's COoperative Valuation in Europe (ALCOVE) Recommendations, International Journal of Geriatric Psychiatry, 29: 682–693
- Brooker, D. and Latham, I. (2016) *Person Centred Dementia Care: Making services better with the VIPS framework*. 2nd edn. London: Jessica Kingsley Publications
- Kitwood, T. and Brooker, D. (ed.) (2019) *Dementia Reconsidered, Revisited: The person still comes first*. London: Open University Press

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