

Dementia and End of Life Care

Welcome!



Care and support when it matters most

Warming Up....

- What are the challenges to promoting good end of life care for those living and dying with dementia?

Discuss this with your neighbour and be prepared to feedback

Setting the scene: An overview of dementia & end of life care

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with acknowledgement to Janet Willoughby



Care and support when it matters most

Learning Outcomes

- State a definition of dementia
- State a definition of end of life care
- Name some of the different dementias and prognostication and stages
- Describe the scale of the challenge of dementia in the UK
- Barbara Pointon's Maxims of care

What is dementia?

Dementia



<https://www.youtube.com/watch?v=fmaEqI66gB0>

Some definitions....

- 'Dementia is an acquired global impairment of intellect, memory and personality, but without impairment of consciousness. It is always of long duration, usually progressive and irreversible'.

Lishman (2009)

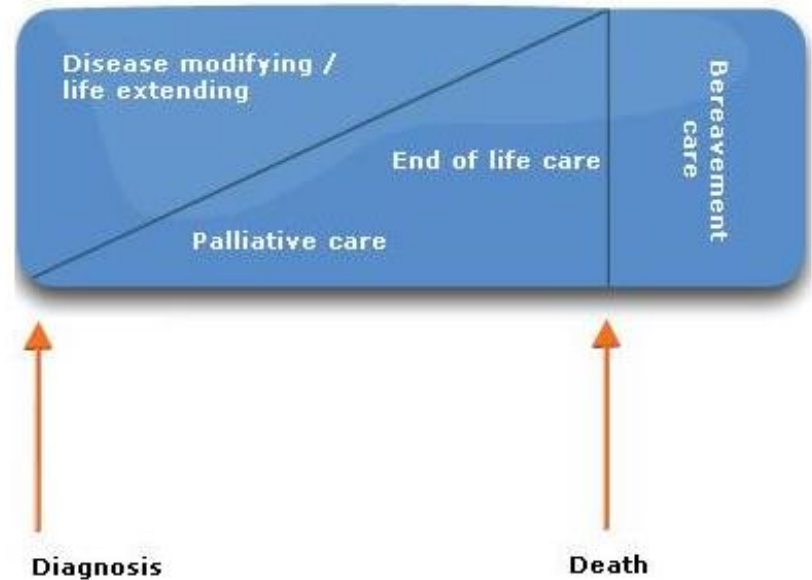
- A condition in which a person loses the ability to think, remember, learn, make decisions and solve problems. Symptoms may also include personality changes and emotional problems. There are many causes of dementia, including Alzheimer's disease. Dementia usually gets worse over time.

WHO 2010

- Dementia is a progressive, irreversible, neurological, incurable syndrome, characterized by widespread impairment of cognitive function. JW!

What is end of life care?

- Care to help all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

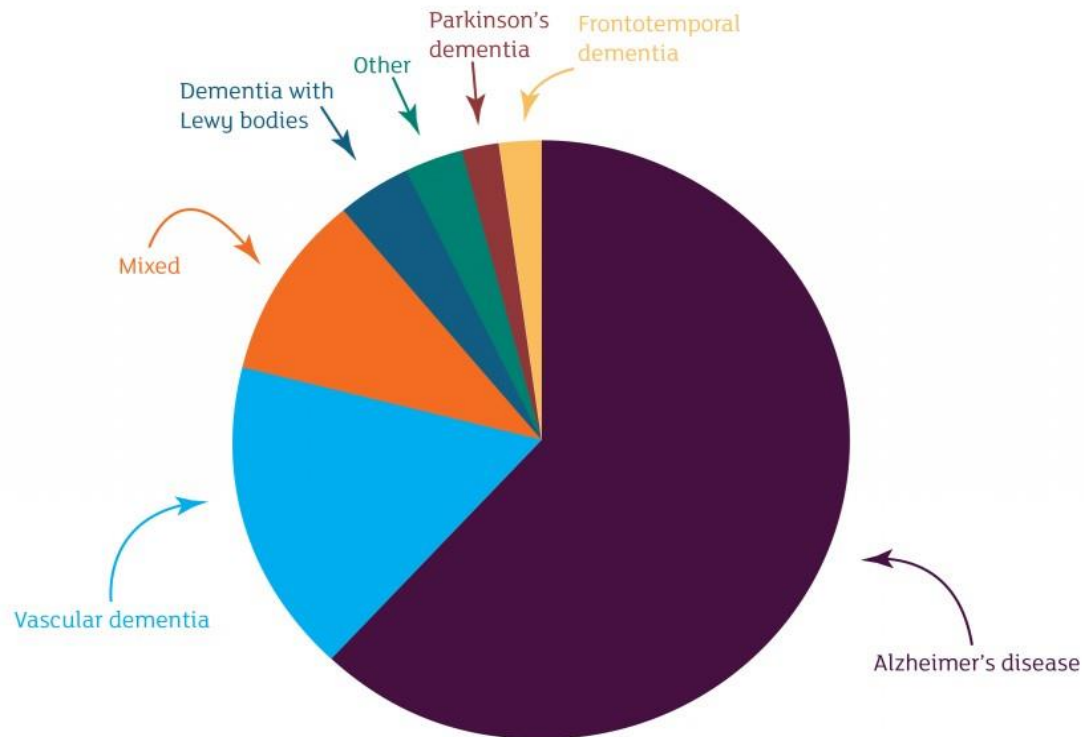


End of Life Care

- People are approaching end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
 - Advanced, progressive incurable conditions
 - General frailty and co-existing conditions that mean they are expected to die within 12 months
 - Existing conditions if they are at risk of dying from a sudden acute crisis event
 - Life-threatening acute conditions caused by sudden catastrophic events
 - GMC (2010)

Causes of Dementia

Causes of dementia



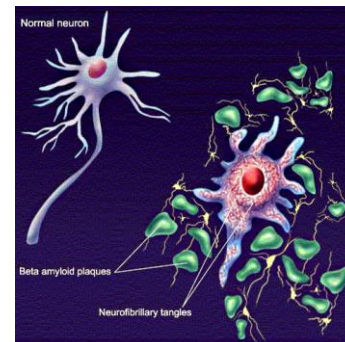
Alzheimers Research UK (2017)

Alzheimers Disease

- Discovered by Alois Alzheimer in 1907
- Most common form of dementia
- Examined brain of 55-year-old woman. She had died after a rapid downhill course of premature senility/dementia
- Saw mass of disordered, twisted protein fragments in place of normal brain cells - “Neurofibrillary tangles” ...

Common Symptoms

- Memory
- Confusion
- Disorientation
- Language
- Mood and behaviour



Vascular Dementia

- Second most common type
- Occurs when blood flow to the brain is reduced
- Two main types:
 - Stroke-related dementia.
 - Subcortical vascular dementia.

Common Symptoms

- Thinking becomes slower
- Personality changes
- Movement problems
- Bladder problems

Symptoms

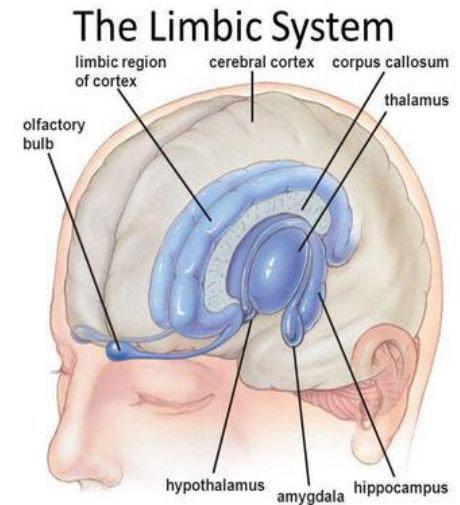
Vascular dementia can have symptoms similar to Alzheimer's and other forms of dementia. These can include memory loss, disorientation and problems with communication.

Dementia with Lewy Bodies

- Third most common cause
- Round clumps of protein causing:
- Low levels of important chemicals (mainly acetylcholine and dopamine) that carry messages between nerve cells
- loss of connections between nerve cells, which then die.
- Good and bad days

Common Symptoms

- Alertness
- Movement problems
- Visual Hallucinations
- Restlessness
- Stability



Frontotemporal dementia

- Caused by damage to the frontal and temporal lobes
- Areas that affect: personality, emotions, behaviour, thinking and language
- Second most common cause of early onset dementia

Common Symptoms

- Personality changes
- Lack of personal awareness
- Lack of social awareness
- Diet
- Behaviour changes

'Other' 5%

- Young onset dementia
- Huntington Dementia
- HIV-AIDs dementia complex
- Progressive Supra nuclear Palsy
- Dementia in Creutzfeldt-Jakob Disease
- Mixed

Stages

Mild

- Needs reminders
- Daily routines difficult
- Concentration is difficult

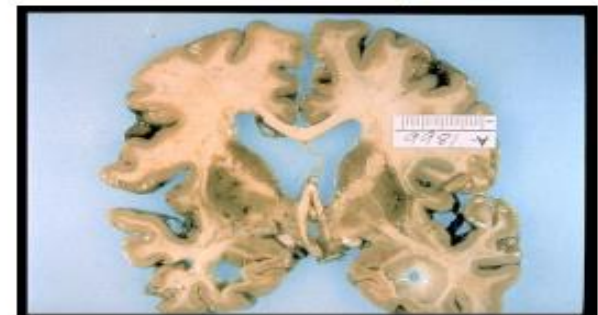
Moderate

- May need hands on care
- May get lost

A significant number will be admitted with cognitive decline- No formal diagnosis

Severe

- Severe confusion
- Needs hand on care for most personal care
- May not recognize self or family



Late Stages of Alzheimers

- Speech limited to single words or phrases that may not make sense
- Needing help with most everyday activities
- Eating less and having difficulties swallowing
- Bowel and bladder incontinence
- Being unable to walk or stand, problems sitting up and controlling the head, and becoming bed bound

Prognosis Profile

- CJD Sporadic 6-12 months
- CJD Variant 14 months
- Young Onset younger the onset, the quicker the decline
- Frontotemporal dementia 2- 10 years
- Vascular Dementia 60% die within 5 years often with other ischaemic/vascular conditions
- Dementia with Lewy Bodies 5-8 years
- Alzheimers Disease 5-8 years up to 10years
- AD & VD (mixed dementia)
- PSP People die ,with, this
- Huntington's disease 10-15 years

End of life care

Factsheet 531LP
January 2017



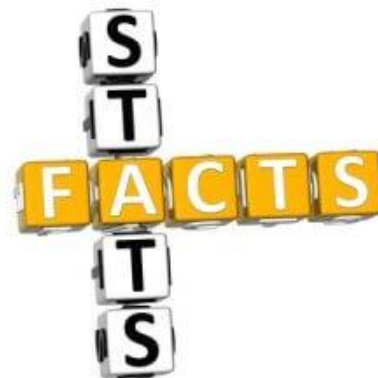
When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them. This factsheet looks at what happens when someone in the later stages of dementia is nearing the end of life, and when they die. It covers what carers can do to support the person, themselves and other close family or friends, and some of the issues they need to consider.

You might not want to think or talk about many of these things. You might find reading this factsheet upsetting. But having these difficult conversations with the person, and planning ahead, can ensure the person's needs are met at the end of their life. It will also help if health and social

What is the scale of the problem?

- 850,000 people in UK with dementia in 2014
- One million people will have dementia by 2025.
- This is set to rise to 2 million by 2040
- 65% of people living with dementia are women
- 60-70% of carers are female
- By 2040 the number of people living with dementia and requiring palliative care will quadruple

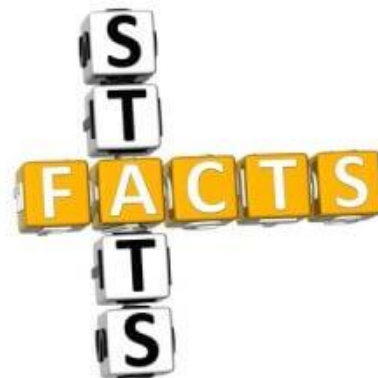
<https://www.dementiastatistics.org/statistics/prevalence-by-gender-in-the-uk/>



What is the Scale of the problem?

- On average those with dementia have 4.6 chronic illnesses
- The carers of those with dementia have a 40% increase risk of becoming frail themselves
- The prevalence of dementia in care homes has risen from 56% in 2002 to 70% in 2013
- Approximately 55% of people living with dementia are in the mild stages, with 32% in the moderate stages and 12% in the severe stages.

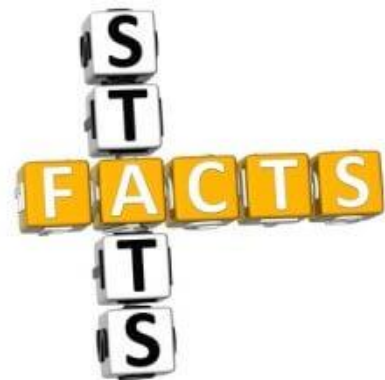
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What is the scale of the problem?

- Care homes set to be the main place of death in the future
- Most people die with dementia rather than from it
- 25% of hospital beds are occupied by people living with dementia who are over 65.
- 20% of hospital admissions of people living with dementia are for preventable conditions.
- 42% of unplanned admissions to an acute hospital of people over 70 have dementia.

<https://www.dementiastatistics.org/statistics/prevalence-by-gender-in-the-uk/>



How should we respond?

8 Maxim's of Care

1. People with dementia understand far more than given credit for: don't exclude them from conversation- take care what is said in presence.
2. Don't rush people with dementia- give them time to do things in their own way and pace.
3. Don't 'boss' : fine line between caring and controlling- no-one likes the latter
4. Who is it a problem for us or them? Go with the flow- does it matter if eats with fingers?
5. Provide choice and celebrate what they can do rather what they can't.
6. There is always a reason for behaviour/ agitation –all behaviour is purposeful.
7. If they can't enter our world then we must enter theirs- be prepared to travel back in time and enjoy their adventures- who cares who the PM is?!
8. Reach out to the frightened person behind the illness- they need to feel safe; respected and cherished.

Barbara Pointon

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