



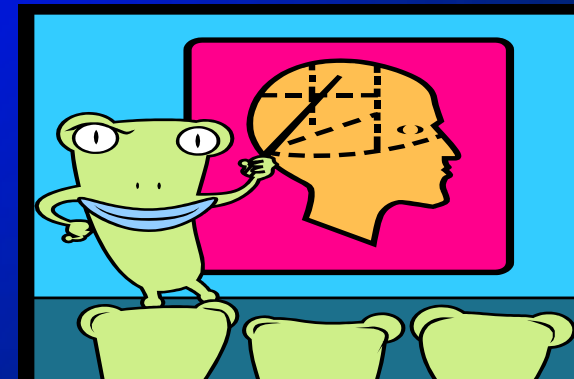
Dementia & Palliative Care

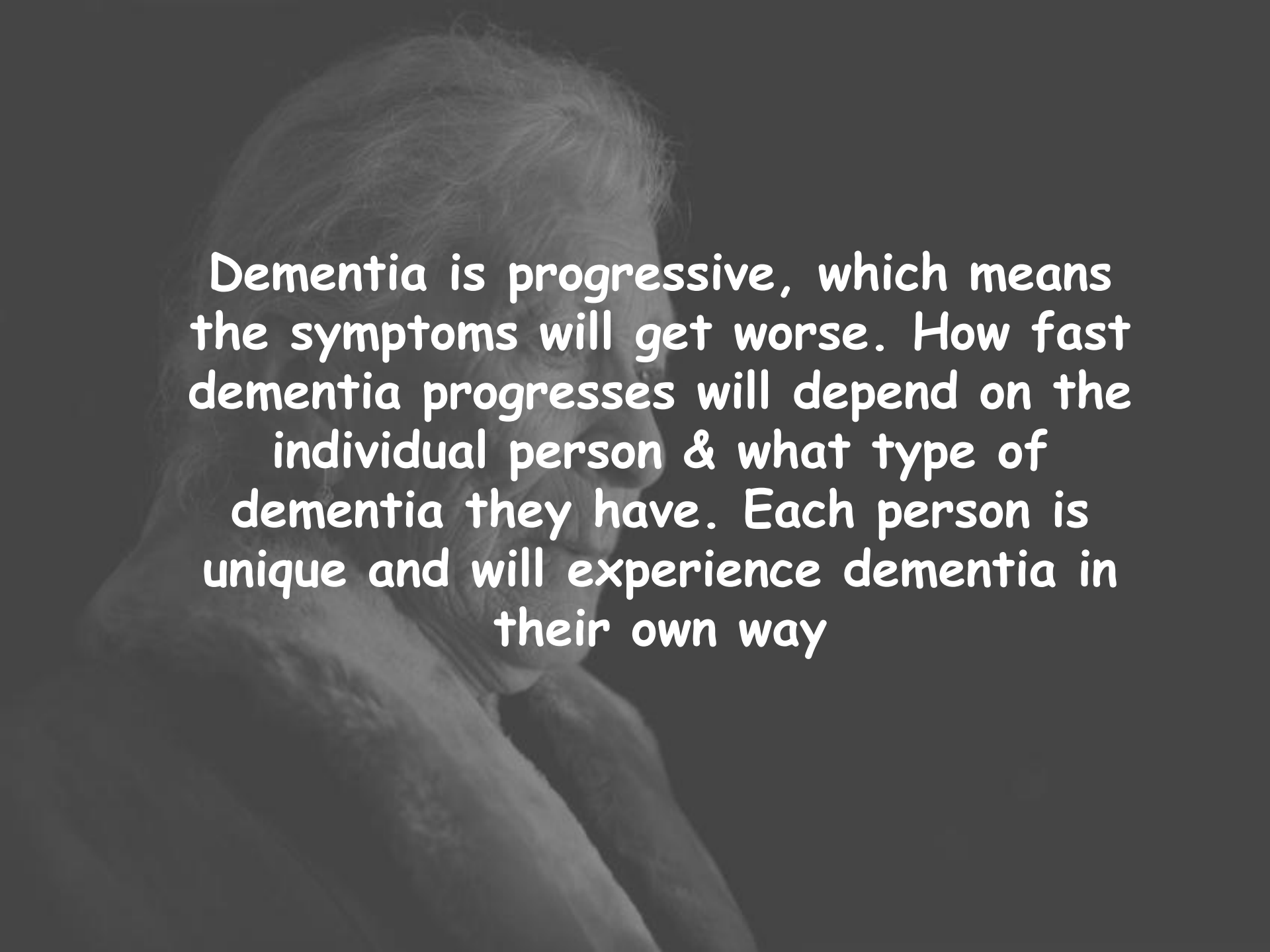
*Aspiration, Myth or Reality?
A Clinicians Perspective.....*

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Dementia

Dementia is a chronic progressive mental disorder that adversely affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement





Dementia is progressive, which means the symptoms will get worse. How fast dementia progresses will depend on the individual person & what type of dementia they have. Each person is unique and will experience dementia in their own way

Facts.....

- Affects 570,000 people in England
- By 2020 estimated there will be over million people with dementia in UK & 1.7 million by 2050
- 1 person diagnosed every 3.2 mins in UK (This equates to 1 new case every 7 seconds seconds WW)
- More common in women
- Affects 1 person in 20 over 65yrs and 1 person in 5 over 80 years. There are also over 17,000 people in the UK under 65 with dementia
- Disease trajectory can last for many years



Treatment of Dementia

- There is no cure
- Main aim should be enabling person to live well with the disease
- Reduce risk factors
- Very few medications licensed for dementia
- Most of these licensed for Alzheimer's disease

Palliative Care?

“Palliative care is an approach that improves the quality of life of the patient and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

(WHO 2002)

Is dementia a life limiting illness?

Progressive illness for which there is no cure

Recently acknowledged as a life-limiting illness

Disease trajectory can last for many years

Current focus is on living well with the illness



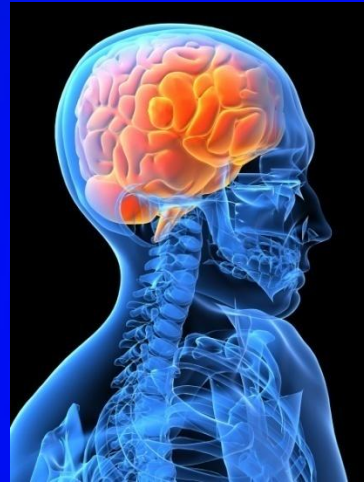
When do you stop living with dementia and start dying from dementia?

Can you die from dementia?



Dying with & from Dementia?

People may die with a complex mix of mental & physical problems where dementia is not the primary cause of death



People may die with a medical condition not related to the dementia e.g. Cancer

People may die as a result of an end stage dementia



- People with dementia receive sub-optimal and inadequate end of life care, more specifically they receive less analgesia than any other patient group
- It is estimated that approximately 100,000 people with dementia die each year in the UK



Can a palliative
approach be applied to
dementia care ?



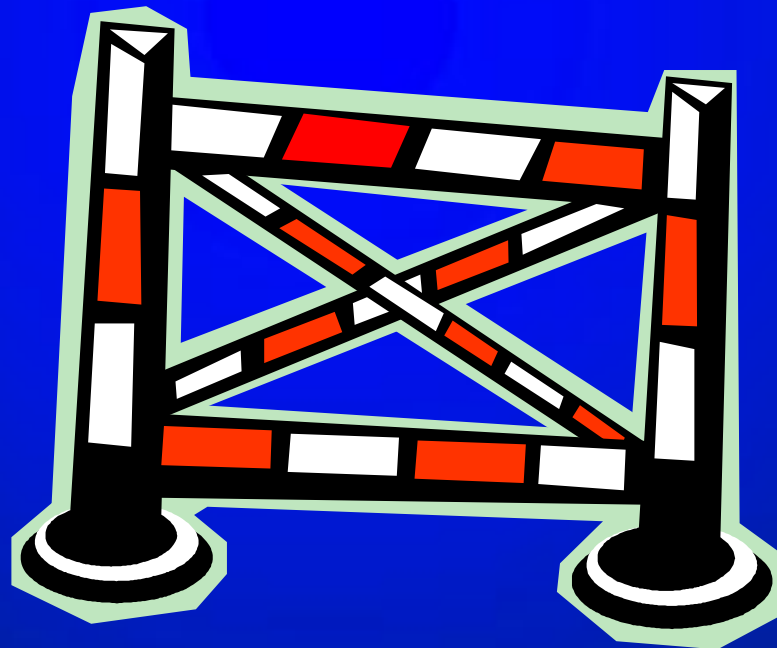
Health and social care professionals working with people with dementia and their carers should adopt a palliative care approach. They should consider physical, psychological, social and spiritual needs to maximise the quality of life of the person with dementia and their family.

(NICE 2007)



What are the challenges /
barriers to promoting a palliative
approach to dementia ?

(My musings based on practice!)



- Lack understanding of dementia & life limiting condition & how it can affect the person
- Loosing sight of the 'person'
- When does palliative care begin?
- Focus on living well with dementia
- When do you have those conversations?
- Medical view of need to treat
- Treatments not taking into account where the individual is in their illness
- Co existence of other conditions - balancing that with where an individual is in their dementia
- Long disease trajectory (Life expectancy from diagnosis to death is around 4.5 years Xie *et al*/2008)
- Outside care providers area of expertise - 'comfort zone' - palliative & mental health. Fear of overwhelming services

- Deterioration in communication and understanding makes it difficult for people with dementia to express their views & symptom report
- Symptoms can be exhibited via behaviour e.g. pain / aggression, terminal agitation / driven movement
- Difficulties with prognosis
- Advanced care planning still in infancy
- People with dementia can live for many years in a frail state that would normally meet recognised prognostic indicators

- Ethical dilemmas around withdrawal and withholding treatment, nutrition and hydration - exacerbated by issues of mental capacity
- Difficulty in accurately diagnosing dying phase - fear of getting it wrong - Assessing when the dying phase has been entered and how symptoms can be managed can be complex when an individual is no longer able to verbally communicate. Often relies on interpretation of behaviour
- Atypical presentations (length and speed of dying phase & symptoms)



Delivering EoLC

Know the person!

Life story work

Music

Massage

Animals

Scents

Likes

Reading

Being with

Talking

Explaining



Delivering EoLC

- Advanced care planning
- Timely assessment - do not be afraid to diagnose
- Observe and interpret behaviour
- Symptom control & anticipatory prescribing
- Think about methods of symptom control - e.g. sub cut v syringe driver
- Open / honest communication
- Shared care /get expert advice
- Time
- Being with - person, family

- Dignity
- Personalisation - what is meaningful to the person
- Adoption of evidenced based pathway - LCP
- Support - individual, relatives, staff
- Accept length of dying phase very individual
- Training, support, supervision
- Review and reflect
- Policy / protocols

Palliative Care & Dementia

Myth

Aspiration

Reality



Palliative Care & Dementia

Aspiration!



Some final words

Dad ended his days on the Ward whom I have nothing but praise for. They cared for Dad and the whole family in his final hours, even the Matron and Nurses put curtains up in a newly painted room to enable our large family all to be with Dad, which is just the way Dad would have wanted things but not what he would have got in any other hospital.

Dads room was our private little world, thank you for creating that special place for us

I am so glad we all had the chance to spend those final days with dad. I can't thank you enough for that and the time spent with us making sure we were comfortable and explaining everything that was happening

We would like to thank you for all your care, and support and help you gave us as a family



Thank You

