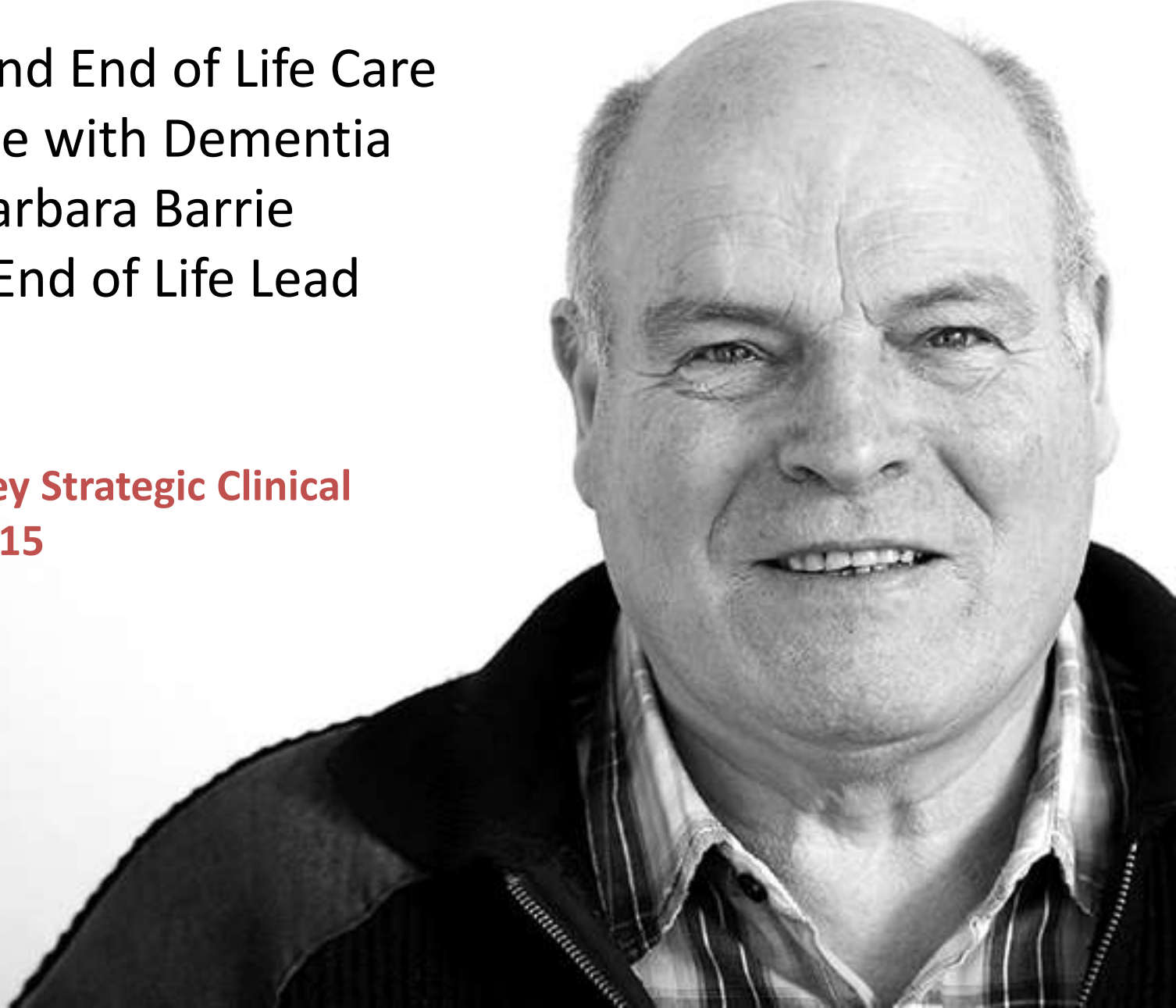


Palliative and End of Life Care for people with Dementia

Dr Barbara Barrie

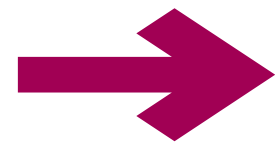
TVSCN End of Life Lead

**Thames Valley Strategic Clinical
Networks 2015**



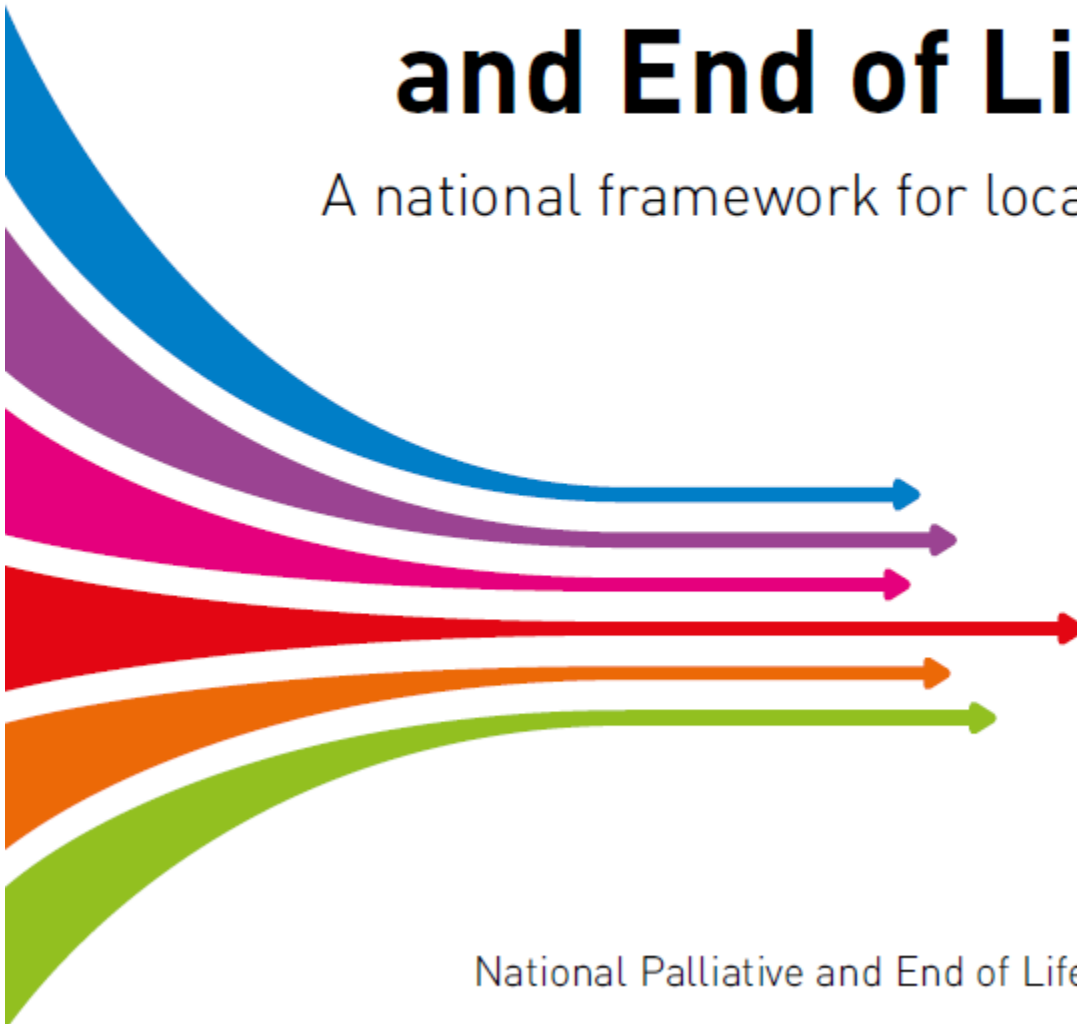
“Care of the dying is the litmus test
of the NHS....”

**End of Life care is everybody's
business**



Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

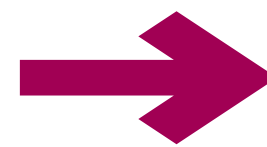
Six ambitions to bring that vision about

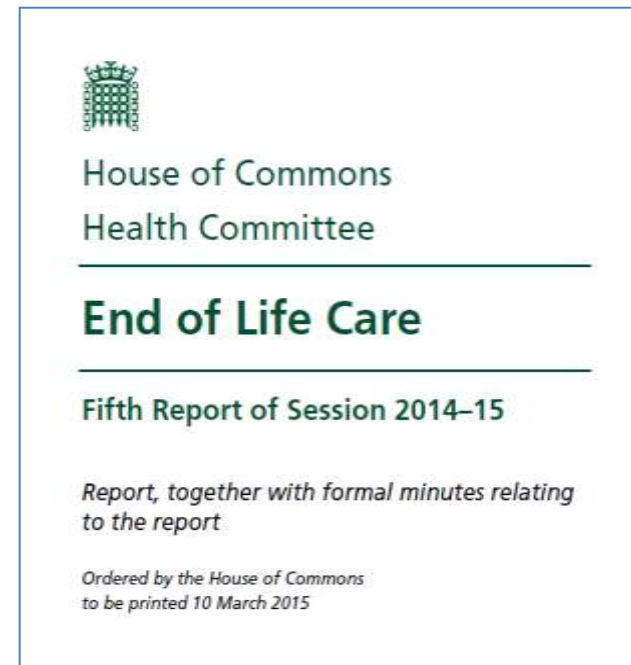
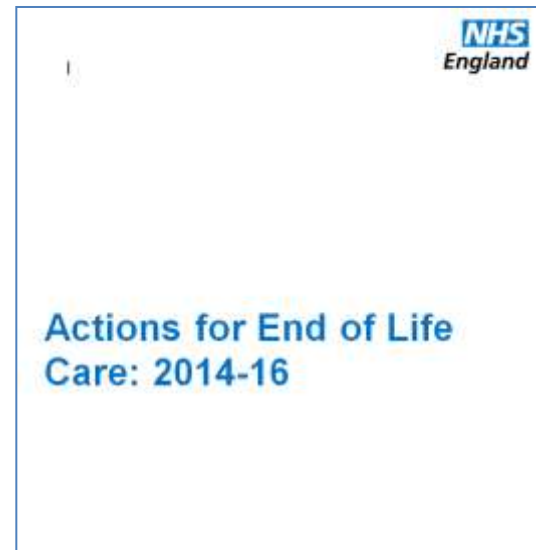
- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."



National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk



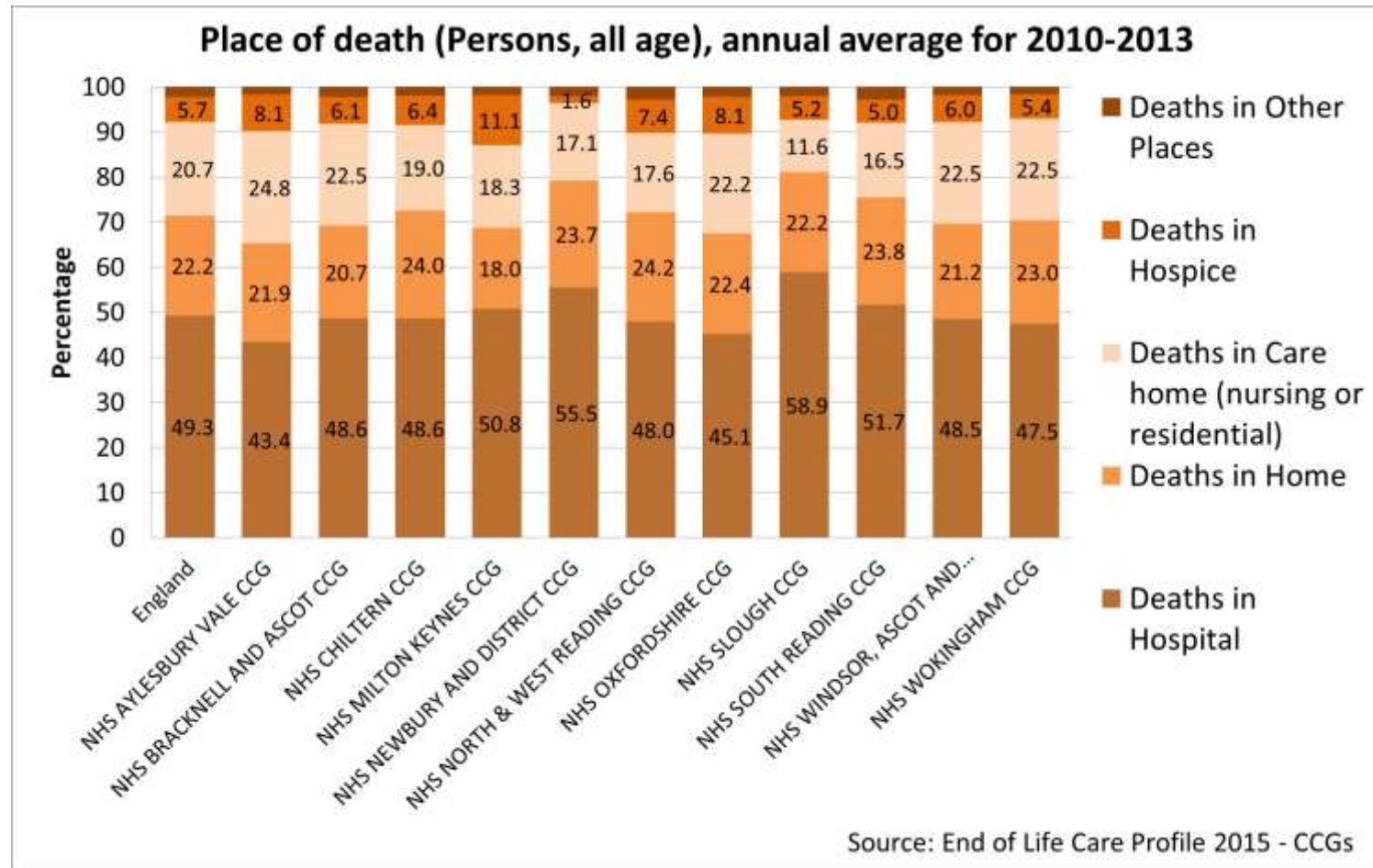


What is a good death?

- 34% of patients ranked “dying in preferred place” as important
- 33% wished to “have as much information as possible”
- 33% wished to be able to “choose who makes decisions about my care”

End of Life Care

End of Life Care is everybody's business



A 16% variation in deaths in hospitals exists across Thames Valley

End of Life Care

End of Life Care is everybody's business



National Survey of Bereaved People (VOICES) by CCG

Combined data from the 2011 and 2012 VOICES surveys

Session	Overall quality of care	Dignity and Respect		Support for carer and family		
Question	Q51. Overall, and taking all services into account, how would you rate his/her care in the last three months of life?	Q14. Overall, do you feel that the care he/she got from the district and community nurses in the last three months was excellent?	Q19. Overall, do you feel that the care he/she got from the GP in the last three months was excellent?	Q46. Were you or his/her family given enough help and support by the health care team at the actual time of death?1	Q47. After he/she died, did staff deal with you or his/her family in a sensitive manner?	Q49. Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?
Answer	Outstanding/Excellent	Excellent	Excellent	Yes, definitely	Yes	I was involved as much as I wanted to be
England	43.21%	78.62% (26,000 respondents)	72.40%	59.76%	93.53%	77.93%
NHS Aylesbury Vale	41.68%	73.33% (n=63)	76.85%	55.32%	94.84%	80.90%
NHS Bracknell and Ascot	46.55%	82.39% (n=21)	73.74%	59.47%	96.14%	74.47%
NHS Chiltern	43.19%	79.08% (n=109)	76.45%	59.78%	94.09%	80.41%
NHS Milton Keynes	38.40%	78.50% (n=73)	69.09%	53.80%	93.12%	76.06%
NHS Newbury and District	44.81%	86.97% (n=37)	79.69%	54.69%	95.75%	81.98%
NHS North & West Reading	48.20%	87.97% (n=47)	68.56%	66.31%	96.34%	89.95%
NHS Oxfordshire	47.09%	80.73% (n=242)	74.99%	59.03%	92.79%	78.88%
NHS Slough	31.93%	55.14% (n=22)	56.52%	52.70%	91.16%	63.95%
NHS South Reading	26.91%	63.01% (n=23)	61.56%	66.92%	91.40%	68.41%
NHS Windsor Ascot and Maidenhead	37.52%	82.66% (n=47)	65.41%	54.44%	92.30%	76.39%
NHS Wokingham	49.08%	80.26% (n=57)	81.93%	59.68%	91.31%	84.67%

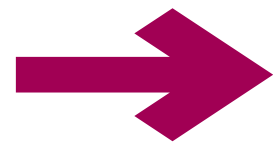
Key	Above national average	Below national average
------------	------------------------	------------------------

VOICES - England, 2014 was published on 9th July 2015

<http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2014/stb-voices-2014.html>

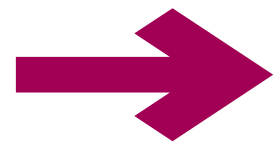
facts

- 2 in 5 people with dementia die in hospital
- Less than 5% of dementia patients die at home /hospice
- Care home bed provision is reversing the trend
- Home/hospice death more likely in affluent areas, female patients, those with cancer as underlying cause of death, less likely in unmarried



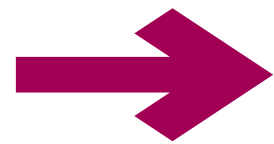
facts

- Dementia is leading cause of death in women over age 80 (16%)
- Death rates from dementia are increasing as people are living longer
- Patients with dementia living in community have higher rates of transfers of care in period close to death

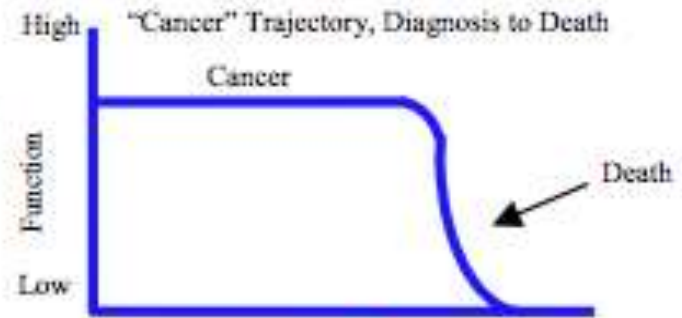
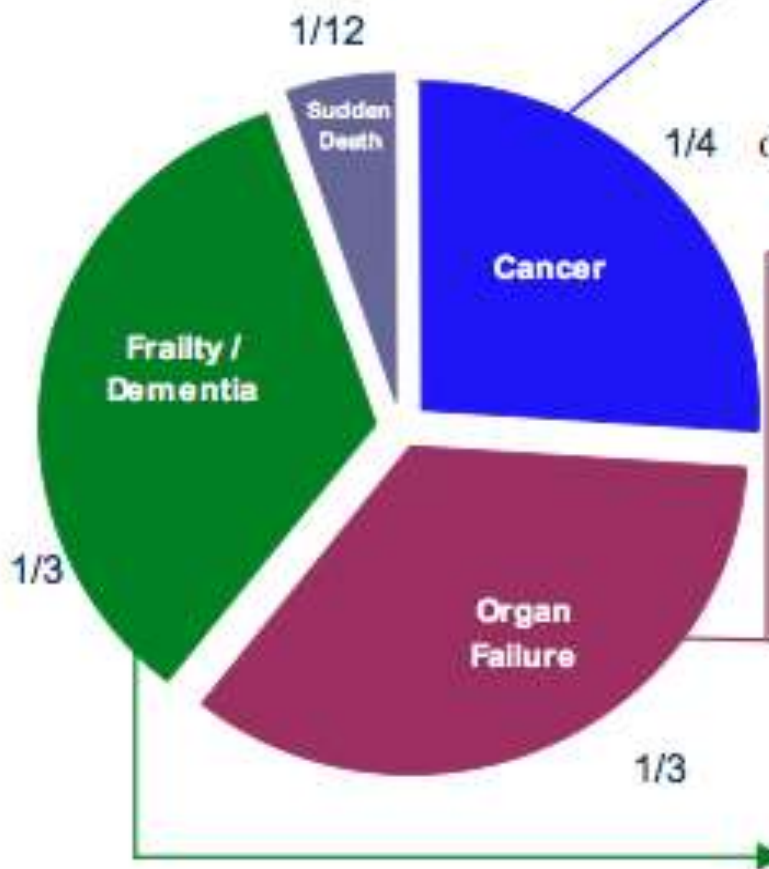


“Death and dying should be a natural matter to discuss...Palliative care for me, starts, should start, the minute that you get a diagnosis...This business of dying is quite a natural process. People tend to regard dying as something unnatural, but it isn’t”

Peter Ashley, living with dementia.



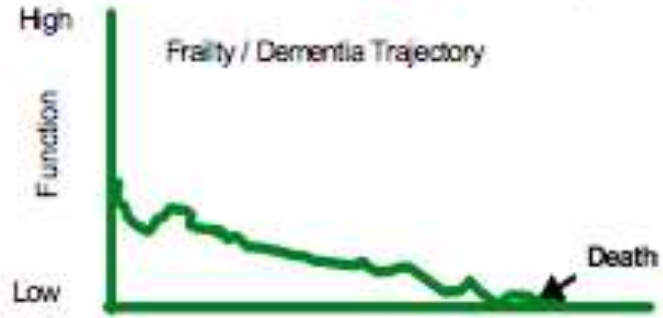
GP's workload - Average 20 deaths/GP/yr (approximate proportions)



Onset of incurable cancer → Time – Often a few years, but decline usually seems <2 months



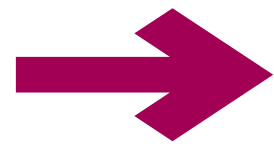
Begin to use hospital care, self-care becomes difficult → Time – 2-5 years, but death usually seems "sudden"



Onset could be deficits in ADL, speech, ambulation → Time ~ quite variable - up to 6-8 years

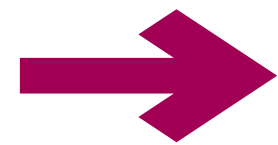
Key issues in dementia at end of life

- Public awareness
- Care planning and proxy decision making
- Dignity
- Pain
- Withholding and withdrawing treatment
- Emotional and spiritual concerns
- Place of death and care



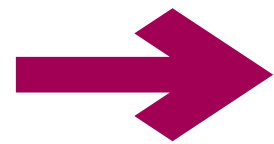
Key barriers to care

- Identification and planning
- Inequality of access
- The quality of care experienced by people with dementia



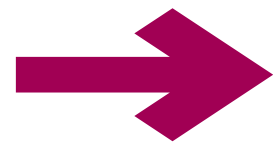
Challenges in providing good palliative and end of life care to patients with dementia

- Unpredictable disease trajectory
- Slow decline in function
- High prevalence of neurobehavioural symptoms
- Loss of capacity –issues around decision making /disease management
- Difficulties in communication



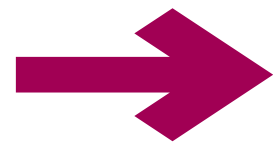
Challenges for Professionals

- Unwillingness to discuss death and dying
- Communicating insensitively
- Overlooking other health conditions
- Difficulty with decisions
- Not considering emotional /spiritual needs
- Not involving family /caregivers in decision making



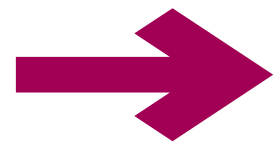
How can we make things better?

- Dementia used as a key example of why planning throughout life is important
- Greater recognition of dementia as a terminal illness
- Dementia friendly communities
- Earlier identification and care planning
- Education Education Education
- Promoting dignity



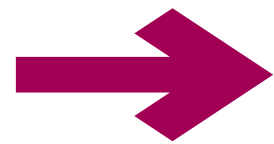
How can we make things better

- Improving symptom identification and control
- Significant, co-ordinated and holistic support when decisions are made around withholding/withdrawing treatment
- Addressing emotional and spiritual needs (including those of carers) and offering bereavement support
- Robust 24/7 services



How can we make things better?

- Commissioners developing alternative models of care to meet the needs of patients
- Use of commissioning levers to improve care
- Developing local metrics and outcome measures
- Capturing patient and carer experience
- Targeted research



**“You matter because you are you, and
you matter to the end of your life”**

Dame Cicely Saunders (1918 -2005)

Thank you –Questions?

**Thames Valley Strategic Clinical
Networks 2015**

