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End of life care for residents with  
dementia  
The Care Homes Challenge

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# Sanctuary Care

- Part of Sanctuary Care, UK's largest housing association: social housing and market rented
- 33 care homes for older people including 10 specialist nursing homes ( dementia)
- 12 Extra Care schemes
- 3 home care agencies in South West England

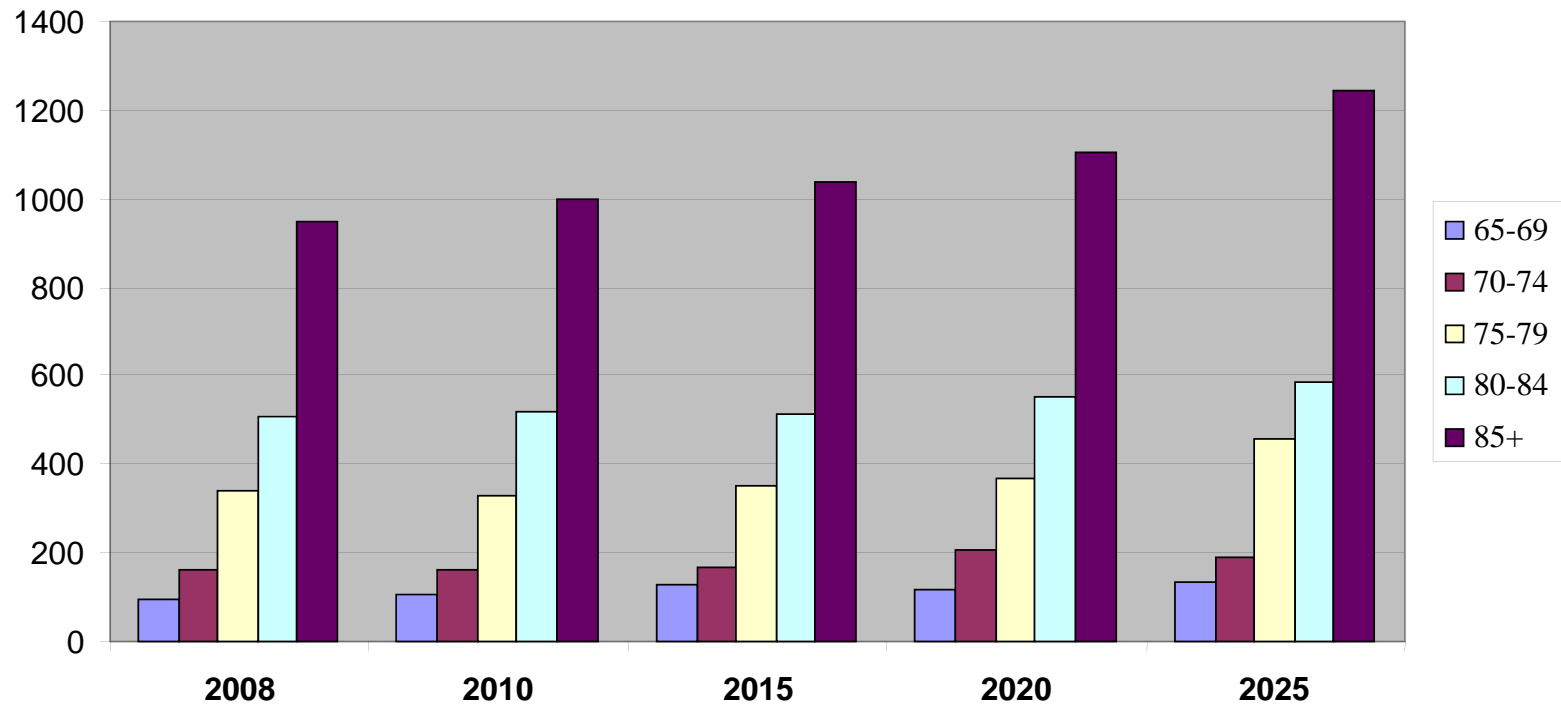


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# Overview

- ❑ Population needs: who is living with dementia?
- ❑ Death as a common feature of life in care homes
- ❑ Bad press: care homes as a focus of concern about standards and quality
- ❑ Skilling up the work force
- ❑ Promoting better outcomes for residents: best practice and new models of care

# People aged 65 in Sutton predicted to have dementia 2008 - 2025





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# Care home trends

- 10,413 care homes for older people: 369,465 registered places (31 March 2009)
- People with dementia occupy 217,030 these beds
- Steady growth in places – mainly nursing homes,
- Places in residential homes fell between 31 March 2008 and 31 March 2009.
- Market is increasingly shifting away from residential to specialist nursing home care



# Challenges in care homes

- More residents with higher levels/complex needs
- Level of understanding of the impact of dementia on individual and skills uneven
- Standards of EOLC in homes inconsistent
- Symptom recognition and control often poor
- People with dementia experience high levels of suffering and sub-optimal care.
- Built environment often 'not fit for purpose' of supporting residents who are dying
- Personalisation
- Inappropriate admission of resident to hospital at EOL

# Care homes: the last resort?

- ❑ 'Old culture' of care: task centred
- ❑ Biomedical model of dementia
- ❑ Social exclusion and stigma
- ❑ Low pay and low status of staff
- ❑ Care homes as 'departure lounges'
- ❑ 'Miserable' residents waiting for death





# Admission and risk to life

- Between 50%-60% of people admitted to care homes die within the first 2 years.
- Mortality rates are highest in the first 6 months and then level off
- Survival of patients with advanced dementia usually < than a year
- 3 most important reported immediate causes of death were:
  - Cachexia/dehydration (35.2%)
  - Cardio-vascular disorders (20.9%)
  - Acute pulmonary diseases (20.1%) mainly pneumonia



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# Predictors of death in a care home

- Age, sex, functional limitation, and malnutrition is stronger predictor of death for patients with Alzheimer's disease in nursing homes. ALSO
- Having a malignancy (cancer)
- Increased age
- Being male
- Malnutrition
- Having limited physical function
- Having a respiratory illness such as COPD
- Having pressure ulcers.



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# Best practice

- ❑ Education and training in relief of physiological symptoms and discomfort using the end of life care tools.
- ❑ Use of an established EOL assessment tool for use with the patient/resident with dementia
- ❑ Pain management ,appropriate medication and care
- ❑ Collaborative working - with GPs, District Nurses, Admiral Nurses, nutritionists, physiotherapists
- ❑ Support for families



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# Safeguards and choices

- The Mental Capacity Act 2005, in particular the provision for Lasting Powers of Attorney
- Enables people to think and plan in advance around money matters, health and welfare issues
- **Personal welfare LPA** gives the attorney(s) the power to make decisions about health and personal welfare, such as day-to-day care, medical treatment, or where the person should live.
- A personal welfare LPA only takes effect when the donor lacks capacity to make decisions



# Sanctuary Care and EOLC

- Liverpool Care Pathway (LCP) used in 60+% of homes
- Training offered by a variety of providers including local hospices and Macmillan nurses
- Link nurses in the homes lead on the work and liaise with external agencies
- LCP offers ‘a good death’ and support for families
- Structured approach helpful given the nature of dementia and when to start palliative care
- Many staff have taken NCFE Palliative Care after NCFE Dementia awareness course



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# Working with families

- ❑ Crucial aspect of EOLC
- ❑ Best practice to involve family from the beginning
- ❑ We identified a need for families to be better informed about dementia, cognitive decline and death
- ❑ Advice about Lasting Power of Attorney
- ❑ Encourage Advanced Decisions
- ❑ Provide emotional and practical support



# Flexible cost effective models

- ❑ Care homes as hospice by design
- ❑ Care homes as community hub for outreach services
- ❑ Sobell House hospice train staff from our Oxfordshire Homes
- ❑ Specialist nurses working with Care Homes e.g. For dementia – Admiral Nurse with Friends of the Elderly and St Christopher’s nurse with Croydon care homes
- ❑ UWE (2008) study of in reach into nursing homes calculated a dedicated team of nursing & physiotherapy provided potential savings of £250,000
- ❑ Partnerships as way forward



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# Promoting good outcomes for residents

‘At any one time a number of residents may be in the end of life phase and so managers and staff should be as prepared for managing the events surrounding this as they are for other aspects of daily life for those with dementia’. NCPC, 2007