

Improving the quality end of life care in dementia

barriers and facilitators to good quality care

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Dementia UK Results

Numbers of people with dementia and projections

683,597 people with dementia in the UK today

"700,000"

In 30 years – doubling of prevalence to 1.4 million

424k in the community (64%)

244k in care homes (36%)

Dementia UK Results

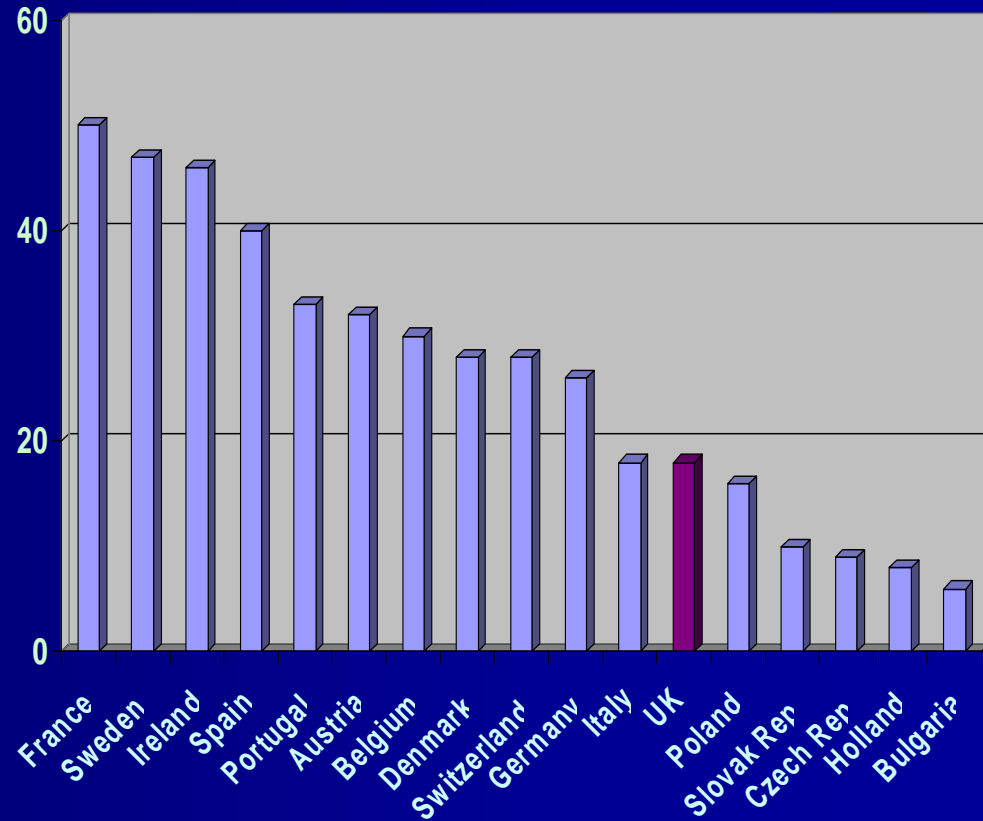
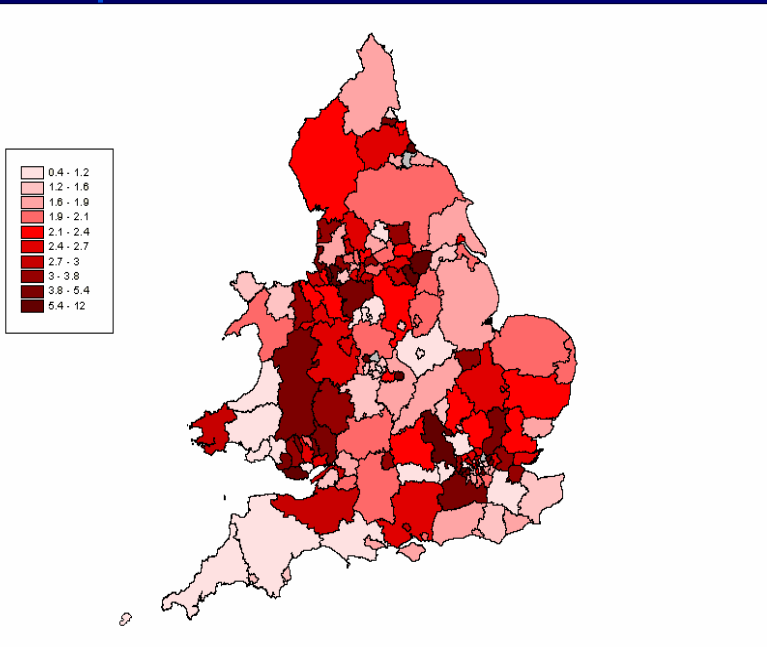
Costs – the answer

Total cost of dementia in the UK
£17 billion per annum

Projected increase in costs of dementia

Total cost of dementia projected in the UK in 30 years
£51 billion per annum

Variation in services for people with dementia – a case study of prescriptions per year per person with dementia 2005-6



National Dementia Strategy development

- 12 month programme
- Develop
 - National Dementia Strategy
 - Implementation Plan
- First explicit prioritisation



Transforming the Quality of Dementia Care

Consultation on a National Dementia Strategy



From the consultation

- Importance of EOLC
- Lots of questions
- Some emerging answers
- Specific issues in dementia
 - Capacity
 - Timing of input
 - Lack of empirical data
 - Nature of the problem
 - effectiveness of solutions

This session

- Not a review of existing demonstration projects
 - Lots to excite
- Focus on starting to fill in the gaps in one area
- What makes for good and bad quality eolc in dementia?
- What are the facillitators and barriers to such care?

Qualitative Research Design

Grounded Theory Approach using Individual In-depth Interviews:

- 27 bereaved carers of people with dementia:
 - 11 died in continuing care,
 - 5 in care homes,
 - 5 in the community,
 - 6 in general hospital
- 23 care professionals (within continuing care wards, CMHTs, care homes, general hospitals, palliative care and liaison psychiatry)

Preliminary findings

Advance Care Planning

“By the time they know it’s dementia they won’t be rational enough to make those sorts of choices and I wouldn’t have thought it was worth agonising over, I really wouldn’t. The important thing is warmth, care, food, beyond that is not likely to matter at all.” (Bereaved Carer 11, Continuing Care)


- Considered a peripheral issue
- Practical difficulties
 - Getting the timing right, wishes change, can’t always accommodate preferences (e.g. dying at home)
- Care professionals see some advantages, but reluctant to take responsibility themselves
 - Too early, too late; prefer to focus on positives
- Consensus: give everyone the opportunity to discuss ACP
- Need to have the skills to introduce why it may be useful to plan for the future
- As early in the illness as possible

Communication with family and treatment decisions

"Afterwards they had done a scan on her head, they shouldn't have done that without me being with her. She must have been petrified... and then also I think they stopped medication as well that she was on. Oh and then one evening we went in and she complained to me that she had a pain in her stomach, so I told the doctor about this and he said that's alright, we will see to it. I go in the next day and now she's got a catheter fitted... Why's she got a catheter fitted? Oh because she is retaining, and she had that then for about 18 months." (BC21)

- Carers keen to be involved in and updated on every stage of their relative's care
- Carers resented giving up decision-making to care home once relative is admitted
- Staff in continuing care wards more likely to have regular contact with carers
- Very poor communication in hospital
 - Different doctor each time
- Staff valued MDT decisions
- Staff felt that medical professionals better equipped to make treatment decisions than family

“Only their heartbeat is left” *

- Difficult for care professionals to empathise
- Risk of focussing solely on symptoms
- Priority of bereaved carers is staff that “care”
 - Warm, interact, provide individualised care
- Value of knowing the patient in treating symptoms
 - E.g. helps to assess pain, alleviate distress
- Bereaved Carers: continuum of care across settings
 - Continuing Care
 - Care Homes
 - Hospitals

Focus on person
Focus on symptoms

* Deputy Manager, Care Home

Specialist Care

“People with dementia in the advanced stages actually don’t have that many complex needs, it’s actually quite basic care needs that are not being met and failure to see people’s symptoms” (Palliative Care Nurse)

- Support with eating, drinking, hygiene, toileting
 - Focus of bereaved carers’ accounts
- Preventing / managing bed sores
 - Bereaved carers emphasise prevention through exercise
 - Care professionals focus on management
- Identifying and managing pain
 - Focus of care professionals’ accounts

Specialist Care

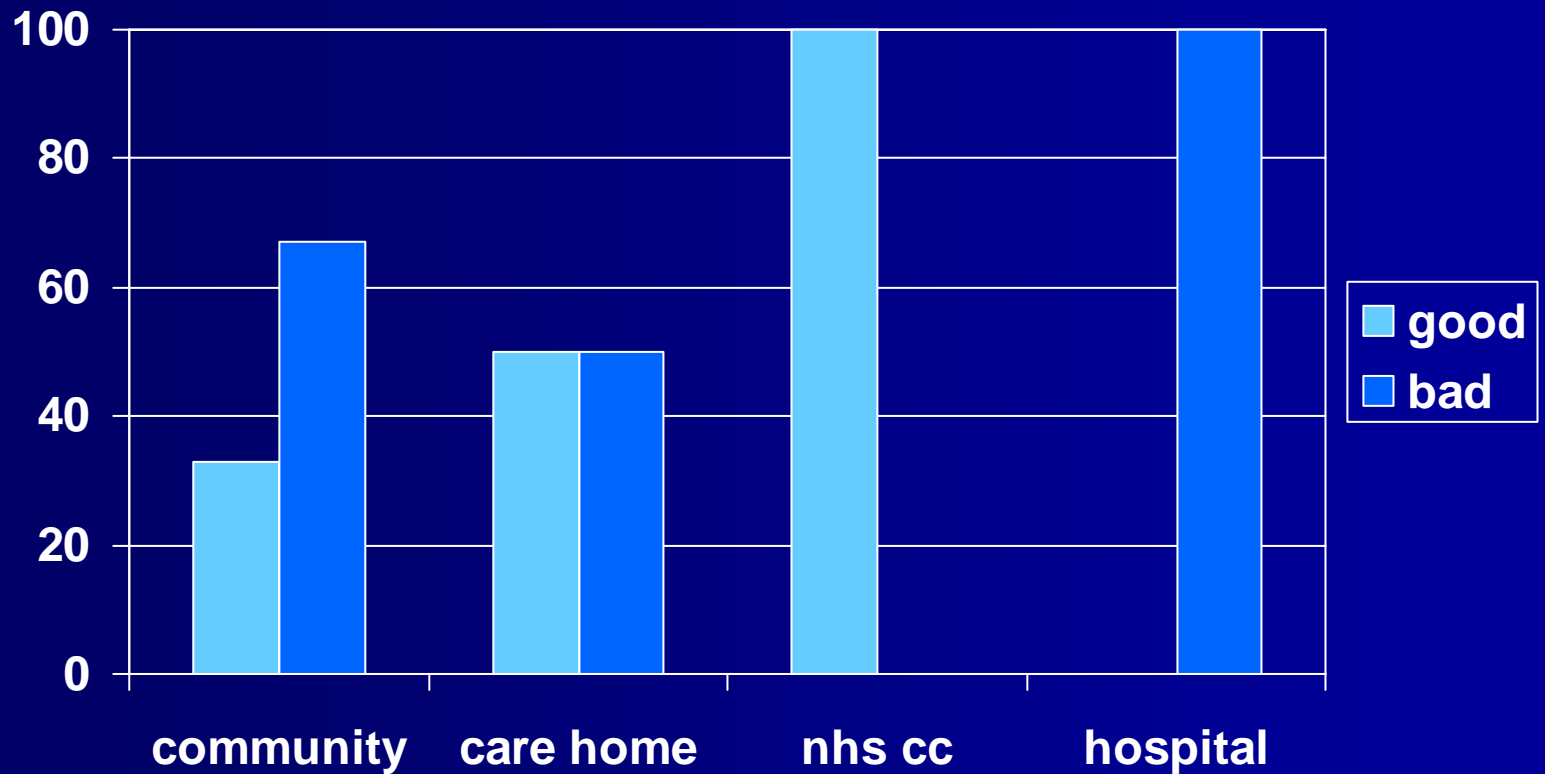
- Confidence to withdraw active treatment
 - Bereaved carers: antibiotics, tube feeding, injections common
 - Liverpool Care Pathway helped in hospital
- Avoid hospitalisation
 - “Let him die at home with his dignity” (Bereaved Carer 25, Community)
 - Complaints of avoidable admissions e.g. dehydration
 - Carers / care homes can lack confidence to manage death
- Increase in palliative input across settings
 - Bolster confidence of staff, pain control expertise

Achieving a good death

"It's not in everybody' nature to positively think about death and I think that's... well for me personally, is around, actually I've spent a lot of time working in a hospice so actually my view of death is very positive in knowing that it can be peaceful and it can be well managed ..." (Charge nurse, General Hospital)

- Planning in advance essential
 - Resuscitation and hospitalization plans
 - Funeral arrangements
 - Emotional preparation cited as valuable to cope with bereavement
- Emphasis on "peaceful death" by both groups
 - Staff in continuing care wards sought to keep patient pain-free, free of complications, in a peaceful environment
 - Conflicted with some carers' wishes to do "everything for their relative to keep them alive"
- Presence of family or other carers in the room during the death important

Quality of death



Conclusions

- All about planning
- All about carer involvement
- All about communication
- Need to know the person has dementia
- Need to modify care to allow for this
- Lots more to know!

Thank you!