

End Of Life Care For People With Dementia: What Do Families Say Is Important?

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Aim

What are the features of 'good' and 'bad' quality end-of-life care for people with dementia from the perspective of family caregivers?

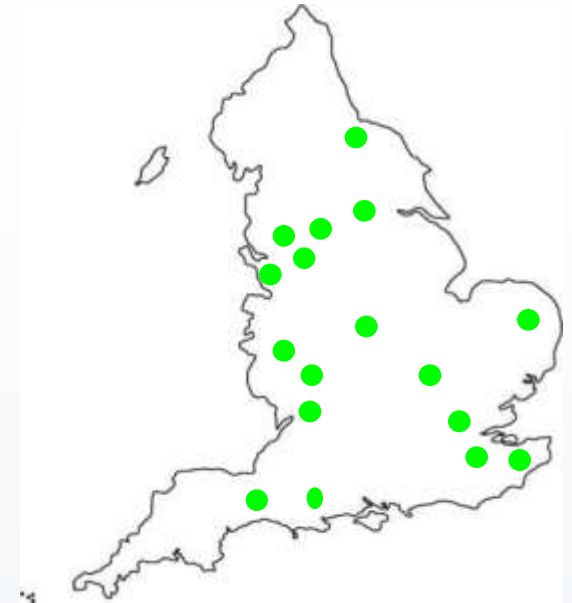
Dementia symptoms at the end of life

- Severe communication impairment
- Incontinence
- Infections (immune system failure)
- Risk of falls/immobility
- Difficulties in swallowing
- Aspiration
- Shortness of breath




What did we do?

- Interviewed 46 family carers in England
 - 31 bereaved
 - 14 currently caring
 - 1 recently diagnosed
- 29 adult children, 17 spouses, 1 close friend
- Bereaved sample range in time from death 3 months – 10 years
- Analysed using thematic analysis methods



What is 'good' quality EOLC for the person with dementia?

- Attention, personalisation and tailoring
- Respect and dignity
- Clothing and appearance
- Compassion and kindness



Develop and change as the dementia progresses

Clothing and appearance

- Own clothing and 'regular' appearance
- Important for two reasons
 - Maintaining the individual, identity and self
 - Comfort/solace of the carer

Clothing and appearance

“When he was in the hospital, you know, I made sure I gave them a whole suitcase full of labeled clothes. And the first time I went to see him, he was wearing somebody else’s clothes, with his glasses had gone, his stick was gone and his hair was wild and he just sort of looked like a wild man”

(062, Daughter, Bereaved)

Clothing and appearance

- “[...] we did find that he was in other people’s clothes and other people were wearing his clothes. And that distressed mum terribly because she, she recognised his clothes. He had very distinctive jumpers and she would practically go and tear them off people. You know, because they were his. She was so protective over him”

(062, Daughter, Bereaved)

Compassion and kindness

What was it?

- Time
- Emotion – warmth, affection and empathy when connecting with individuals
- Understand and appreciate the needs of others

Compassion and kindness

“[...] It’s just a real difficulty at the moment in the NHS, that nurses do not see their role as caring, they see it as some kind of paramedical role. And no, it was completely disastrous.”

(004, Daughter, Bereaved)

“[...] And when he finally did get somebody [GP] to come and see him, he [GP] just looked at him at home and just said to me, ‘Hopeless case.’ [...]”

(031, Wife, Bereaved)

Compassion and kindness

- Structural and organisational pressures?
 - Palliative care started outside the NHS but increasingly integrated within the NHS – *rules, structure, standardized*
 - Changing role of nurses
- Putting up emotional boundaries for protection?

Conclusions

- Many basic elements to good EOLC
- Is dementia EOLC that different to the care throughout the trajectory of dementia?
- Carers think more about the interpersonal and social aspects of care not the technical medical aspects

Thank you

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