

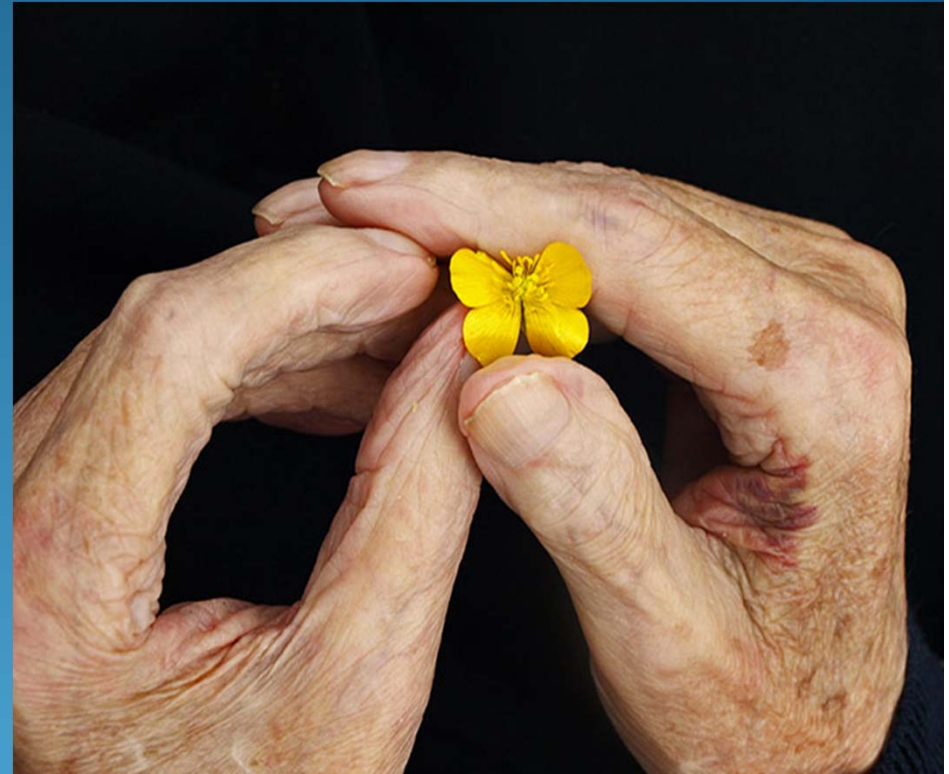
*What do we know about end of life and  
dying with dementia in care homes from  
the family carer's perspective?*

*Jean Hennings  
CECo Scholarship 2009*



# Background

- 24 million people living with dementia
- Care home admission common
- Important palliative care setting
- Role of carers



# Approaching the end of life & dying with dementia in care homes; the accounts of family carers: a systematic review

## Inclusion criteria:

- Peer reviewed papers / empirical research
- Written in English
- Published 1980-2009
- Family members' experiences, needs, views
- End of life with dementia
- Long term residential care setting

# Findings

## Origins

7 North America

1 UK  
1 Australia  
1 Netherlands/USA

## Design

6 Grounded Theory/  
Qualitative

1 Ethnomethodology  
1 Survey  
1 Concurrent mixed  
methods  
1 Prospective cohort  
study

## Methods

7 Interviews/ Focus  
groups

1 Postal questionnaire  
2 Chart review &  
Ethnography or face to  
face questionnaire

# Key themes

Making  
Decisions

The  
Grieving  
Carer

Unfamiliar  
Territory

# Making decisions

- Role of family unclear
- Guilt & anxiety
- Base decisions on previous wishes, preservation of dignity & comfort



# The grieving carer

- Strong personal needs: empathy, reassurance, guidance, communication
- Frequently disappointed
- Death seen as both blessing & tragedy

# Unfamiliar territory

- Lack knowledge & experience
- Don't recognise dementia as terminal illness
- Poor communication
- Palliative care seen as 'giving up'



# Next steps

Hennings J, Froggatt K, Keady J. (2010) Approaching the end of life and dying with dementia in care homes: the accounts of family carers. Reviews in Clinical Gerontology 20(2): 114-127

BUPA Foundation Grant Awarded Dec 2009. Improving end of life care for those with dementia in care homes; a pilot study (£19,982.00 over 1 yr)

PhD. Lancaster University. Spouse carers of people with dementia nearing the end of life in care homes

# Thank you

**5** Cancer  
experiences  
collaborative  
years

