



DementiaUK

Helping families face dementia

Dying to live at home with dementia

www.dementiauk.org

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@DementiaUK

Registered Charity Number 1039404

Where are people dying?

- 55.3 % die in care homes
- 39.6 % die in hospital
- 0.8 % die in a hospice
- 4.8 % die at home

Despite a preference for care at end of life at home

'End of Life' misunderstood

- What does End of Life mean?
- Dementia still not recognised as a life limiting/terminal illness
- Inequitable access to palliative care services
- Limits opportunities for honest, well informed conversations
- Professionals' reluctance to talk about death
- End of life priorities not a normal part of care interventions

What happens in the last year or so?

- Less people dying in hospital but more being admitted to A and E in last 3 months.
- Frequent hospital admissions
- Repeated infections, not responding to treatment
- Eating and drinking problems
- Reduced function and mobility
- Delirium
- Bouncing between services = reactive care, 'nothing we can do'. Decision making too late and in crisis

Family carers

- Preferring to live in the here and now
- Little desire to know how dementia may develop and impact in the future
- People with dementia expecting family to act confidently on their behalf but often wishes not well known
- Unskilled, uncertain and poorly prepared
- Searching for solutions
- Grieving, chronic sorrow
- Distressing transitions + decision making under pressure
- Proxy decision making = significant source of distress
- ACP = discussions in the abstract difficult. Need new patient/family centred models

Harry and Joan

Harry

'It takes me 2 hours to give her breakfast'
'They'll think I'm starving her'
'She's so slow now, takes all day to get anything done'
'Getting up the stairs is getting harder'
'She hardly says a word'

Joan

Alzheimer's disease-
diagnosis of 2 years

Bill and Helen

Bill

'She's trying to leave the house late at night'

'I ended up in hospital with her after ringing 111, no one knew what to do'

'I had to force her to stay in. The carer told the social worker...'

'She's messing everything up, I'm losing important papers'

'She's hardly eating'

Helen

Vascular dementia-
diagnosed 3 years

Michael and Hilary

Michael

'I don't want to change the bed to a hospital bed'
'She's not in pain, I would know'
'I want to care for her at home but they said I can take her to the hospital (MH) if I need to, so I'll do that if I can't cope'
'I'd like her to die at home though'

Hilary

Alzheimer's
disease-10 years

Identifying deterioration

- Fast
- SPICT
- GSF
- IPOS Dem
- Surprise question
- ACP- conversation- a fluid process
- Best interest

Planting seeds, revising care goals

Opportunities at transition points:

- What if you became more ill?
- Where would you like to be cared for?
- What if you developed an infection?
- Would you like to be admitted to hospital or have treatment at home?
- What do you think you, your family and friends would want to know if you became more unwell?
- If your condition worsens, what are your goals, fears?

Symptom management/ comfort care planning

- What keeps the person pain free?
- What makes the person relaxed and happy?
- What brings emotional comfort?
- What brings physical comfort?
- What environment makes the person feel safe and comfortable?

Reducing fear and uncertainty



A guide for carers, families and friends of dying people

Tips as to how...

Resources

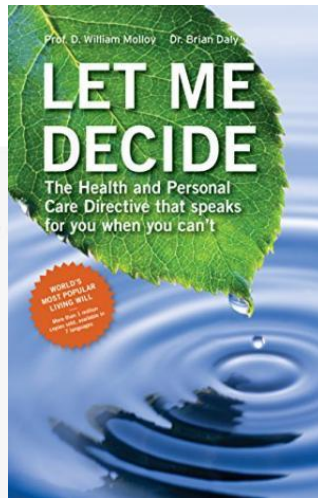
The Conversations Game™

Talking Mats™

FINK cards™

Let me decide.

Difficult Conversations.



Q.

fink™

If I were unable to say what was important to me about my care or treatment – who would I want to speak for me?



Thank you for listening

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**# Admiral Nurse Dementia helpline
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