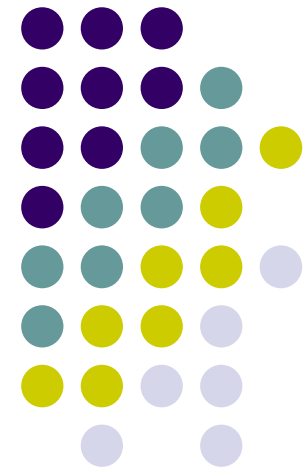


# End of Life care for people with dementia

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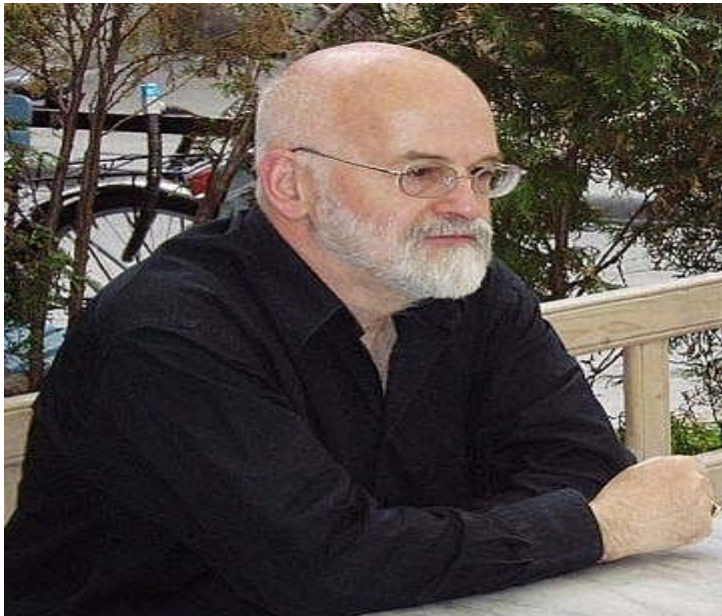


## **BACKGROUND**

## **WHAT WE KNOW**

## **EXAMPLES FROM TWO CARE HOME STUDIES**

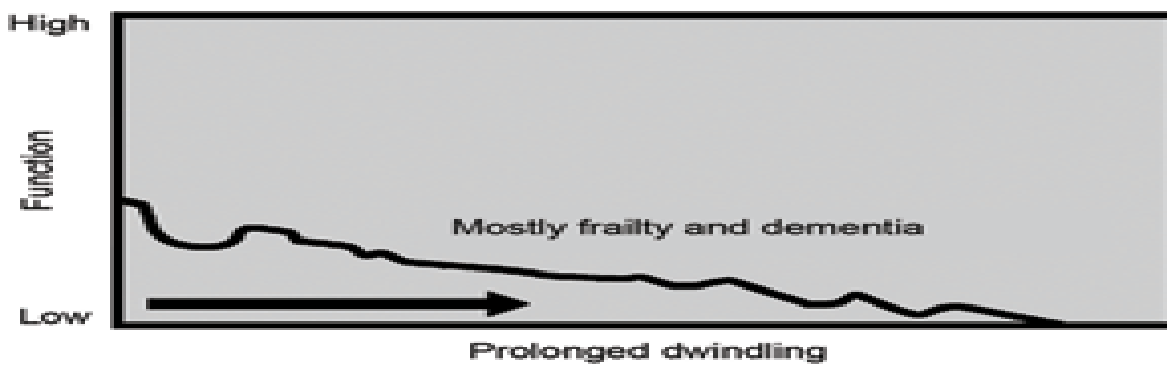
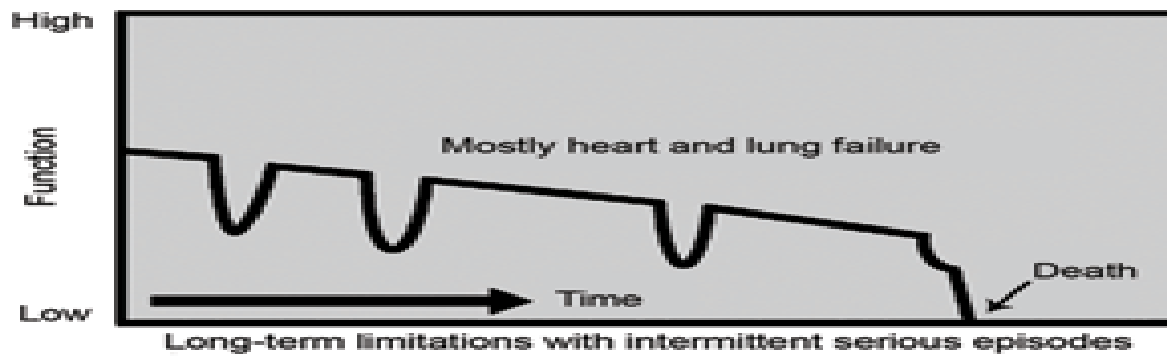
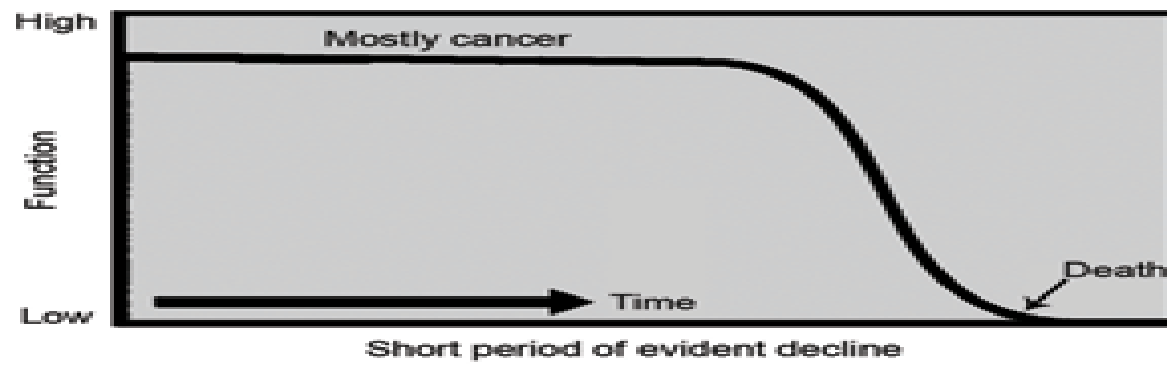
## **EMERGING ISSUES**





## Joanne Lyn (2000)

- *Most of us ... will be disabled for many months or years by diseases such as heart disease, emphysema, stroke, **dementia**, and even cancers like breast cancer and prostate cancer. Along the way, we will have episodes of serious complications. Any one of these episodes can cause death, and one of them will--**but we will not know which one until it is upon us.** . Testimony before the Senate Special Committee on Aging*



# Evidence suggests that



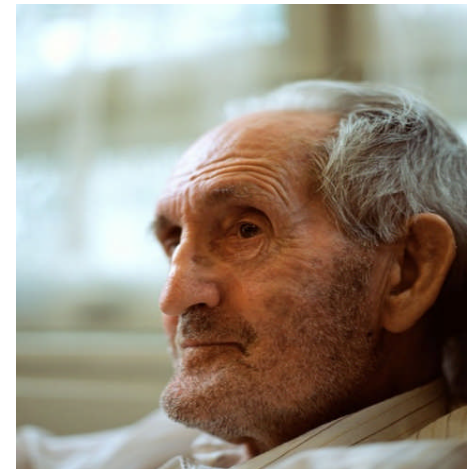
- Compared to other patient groups people with dementia receive less pain relief and fewer medical services
- Decisions not to go to hospital are not made till death is imminent
- Carers experience prolonged loss, including loss of choice and control when someone moves to a care home or hospital ( do need a “goodbye” moment).
- Some approaches to support advance care planning and adapted palliative care tools can reduce unnecessary treatments and admissions to hospital at the end of life.

# Recognising when someone is dying with (or from) dementia influences:



- Decisions to involve palliative care services
- Planning care that involve relatives and staff
- Decisions to avoid unnecessary interventions
- Decisions to transfer older people to a hospital or a nursing home

**BUT**





- End of life care tends to focus on knowing when someone is dying and stopping treatments, not on developing dementia specific interventions
- Need to understand how **interactions between the**
  - context and culture of care.
  - symptoms,
  - beliefs and knowledge of staff, people with dementia and family members
  - different types of collaborative workingAffects how end of life care is provided for people with dementia and their carers



# Issues to consider



- Environment
- Pain, discomfort
- Nutrition
- Communication
- Carers' and family needs
- Capacity
- Preferred Priorities for Care and Advance Care Planning
- Involvement of specialist services



## Current work

- Review of end of evidence for end of life care for people with dementia living at home and in care homes
- Two nationally funded care home (residential) based studies that have tracked the care older people receive over time





# Care homes

- Approx 15,700 care homes providing nursing care and/or personal care to more than 400,000 older people.
- Approx 21% of people over the age of 65 die in care homes (Office of Fair Trading 2005).
- > third of people in care homes have dementia
- A population that has inequitable access to NHS primary care services and in particular specialist and generalist palliative care

# Recognising when someone is dying with (or from) dementia



- 883 older people with dementia <1% recorded as having a life expectancy of < 6m but 71% died during that period (Mitchell et al 2004)
- There are prognostic indicators (e.g. age, global deterioration, dehydration, anorexia, loss of function) but little consensus on the reliability and predictive validity of the different indicators
- Difficult to discriminate between the impact of underlying morbidities, different disease trajectories and dementia



# Resident Health Status

| Care Home               | Mean no. Of Long Term Conditions, (SD) | Mean no. Of acute conditions, (SD) |
|-------------------------|--|------------------------------------|
| 1 (N=20)                | 3.30 (1.30)                            | 0.65 (0.99)                        |
| 2 (N=24 <sup>**</sup> ) | 3.17 (1.61)                            | 0.29 (0.86)                        |
| 3 (N=15 <sup>**</sup> ) | 2.13 (1.60)                            | 0.40 (0.63)                        |
| 4 (N=23)                | 2.87 (1.32)                            | 0.17 (0.65)                        |
| 5 (N=32 <sup>**</sup> ) | 3.75 (1.70)                            | 0.16 (0.57)                        |
| 6 (N=15)                | 2.87 (1.25)                            | 0.20 (0.56)                        |

# Possible Evidence of Physical Decline



| Care Home | Yes | No | Total |
|-----------|-----|----|-------|
| 1         | 14  | 6  | 20    |
| 2         | 17  | 7  | 24    |
| 3         | 8   | 7  | 15    |
| 4         | 10  | 13 | 23    |
| 5         | 16  | 16 | 32    |
| 6         | 5   | 10 | 15    |
| Total     | 70  | 59 | 129   |

# Discussions of Death and Dying



| Care Home | Has been discussed with the person | Not discussed with the person | Not recorded | Total |
|-----------|------------------------------------|-------------------------------|--------------|-------|
| 1         | 5                                  | 2                             | 13           | 20    |
| 2         | 4                                  | 0                             | 20           | 24    |
| 3         | 0                                  | 3                             | 12           | 15    |
| 4         | 8                                  | 8                             | 7            | 23    |
| 5         | 2                                  | 11                            | 19           | 32    |
| 6         | 1                                  | 4                             | 10           | 15    |
| Total     | 20                                 | 28                            | 81           | 129   |

# The person with dementia's view = Heterogeneity of experience and views



- Living in the present
- Acceptance of the future
- Wanting meaning and purpose now
- The past is the present
- Spiritual issues



# Live in the Present (EPOCH)



“Well I don’t know about the future, I just go along day by day” (H2-005)

“No. Not particularly, no. I don’t think when you come to my time of life you do really”[think about the future]” (H3-005-1)

“I haven’t actually thought a lot about that (*laugh*) because I find it not um... suitable subject for contemplation, let’s put it that way” (C1-005-2) [Fieldnotes: however this interviewee did go on to talk about it]

“don’t think about it...I think it’s better not because you don’t know what’s going to happen in the future so you may as well just take it for granted, you know” (C1-009-2)

## Acceptance: Look to the Future (EPOCH)



“Well the future, I think of being here, I’ll be here till I die. That’s my future, I’m quite settled in that really (H1-10-1)

“my future is my funeral isn’t it” (C1-004-3)

### Active Planning for The Future:

“[manager]’s come and talk to me about what I want and what I don’t want and she worked out all the words for me to write down, I’ve still got to write it down and she said that will stay with me because I said I don’t want to be resuscitated, I don’t want to... if I have a fall and I might be injured I don’t mind going to hospital but I don’t want to be kept in unless I’ve broken something and if they decide I’m dehydrated as I read about a case, I said I don’t want to be kept in **I’d rather come back here and dehydrated than in hospital. Well I said that I don’t want to be... If I die I don’t want to be resuscitated if you know what I mean**” (E4-001-2) (View 9)

“You know, you’re not going to get out of this world alive and I want to make it a bit easier and all my children will be terribly upset but, so to me **I have to make it as easy as I possibly can for them**, so I’ve done everything I can to tell them what...what to do” (H3-01-2).

Had ACP and died in the care home

# Wanting meaning and purpose now



- “...what’s the point of it all, I like to be useful but I can’t be useful can I, what can I do to help anybody else, I can’t help, I can’t offer an arm to walk down the shops, I can’t do anything.” *PWD CH2*
- “...I said well why can’t I go for a walk around the grounds, she said “well I can take you when I’ve finished my work” but she was busy so, and it never went any further.” *PWD CH5*

# Living in the Past: Displaced by Time Past is their Present



“Well I don’t quite know really, because I’m a full pensioner and an old age pensioner so you’ve got no option. I might not get a house of my own in [town] and think **it suits the kids more to have me here so that they don’t worry and they can pop in and see me. They don’t want me in their lounge**” (H1-005-1)

“ they’re quite happy to keep me here and then **they pay for me and they pop and see me, but I don’t think they want me in their lounge...**” (H1-005-2)

“I’m just now waiting to be demobbed.....

Well, the thing is, I’m now, born in 1915, so what age am I now?  
Fifty?.....

So I’m now looking forward to retirement from [a retail store] and my old age pension and a bit of savings, I shall be all right...

**What’s Important to you?** to keep healthy and in my little cottage, do the garden, you know” (H1-005-3) taken from EPOCH study

# Interviews with NHS and care home staff



- A recognition of the need for pro-active care and planning BUT
- Recognition that people die in different ways, unpredictability is difficult to deal with
- Not clear who is responsible for end of life care, how discussions and decisions are initiated.
- NHS staff believe care home staff feel anxious, care home staff believe NHS staff lack expertise in dementia care



## Future work on evidence

- Develop ways that care home and NHS staff can review care together
- Discussion and development of what good end of life care might look like for particular residents and their families (and how to incorporate knowledge of the person into those stories)
- Identifying a sub-group of residents who are perceived as likely to benefit from health professionals involvement and ongoing discussion with care home staff

# Future work?



- **How to manage uncertainty**
- How the culture of care shapes decision making
- Review impact of treatment decisions (i.e. medication withdrawal, pain management, feeding etc)
- Development of palliative care support tools for people with dementia
- Interventions to enable collaborative working if a person with dementia is deteriorating/dying)
- Supporting end of life care for people with dementia living at home



# References

Mitchell, SL, Kiely, DK, Hamel, MB. Dying with advanced dementia in the nursing home. Arch Intern Med 2004; 164: 321–326.

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