

Interface of medical & social care systems in Dementia and end-of-life care

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End-of-life care for people with dementia: some themes

- The scale of the problems
- The depth of the problems
- Some possible solutions



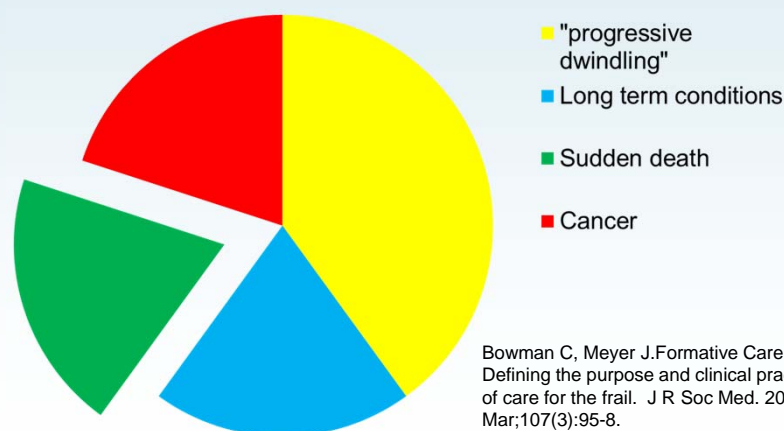
The scale of the problems: 1

- If we survive to 65 years we have a 1 in 3 probability of developing dementia
- Dementia is not a long-term condition
- The incidence and prevalence of dementia may be declining

Alzheimer's Disease International report 2014

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Scale of the problems 2: Causes of death



Bowman C, Meyer J. Formative Care: Defining the purpose and clinical practice of care for the frail. J R Soc Med. 2014 Mar;107(3):95-8.

4

Scale of the problems 3: Dementia is a short-term condition

4.5 years from symptom onset

Xie J et al Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. BMJ 2008; 336: 258- 262

3.5 years from diagnosis

Rait et al, Survival of people with clinical diagnosis of dementia in primary care: cohort study BMJ 2010 Aug 5;341:c3584

5

The depth of the problems

Loss of mental capacity

- What is happening? What do you want to do about it?
- Pain, infection, refusal of food and fluids

Prognosis:

- Frailty adds 'unstable disability' to 'progressive dwindling'
- Family awareness

Anxiety among professionals

- Politicised environment
- Fear of media or legal repercussions

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welcome review of the pathway to death

By DAILY MAIL COMMENT

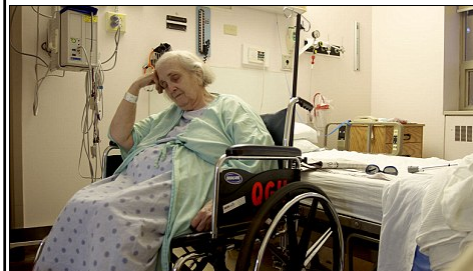
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Until now, the medical Establishment has contemptuously dismissed public disquiet over the Liverpool Care Pathway, the official guidelines under which patients judged to be dying are left without treatment, food or fluids.

In a hugely welcome change of approach, however, the Association of Palliative Medicine has ordered a review of the concerns expressed by countless bereaved relatives, with a promise to explore ways of improving practice.

Among those anxieties, one of the most oft repeated – highlighted in heartbreaking accounts to the Mail – is that loved ones have been put on the LCP without the consent or knowledge of their families.



HOW MAIL HIGHLIGHTED THE STORY

Two doctors must agree to use of 'death pathway'

The Mail, October 2

A LONELY DEATH ON THE 'CARE' PATHWAY

October 15

Police probe the death of mother on care pathway'

October 11

My diary of Mum's awful death on the Liverpool Care Pathway

October 20

Doctors to act on Care Pathway: After Mail campaign, investigation is launched into controversial guidelines on 'hastening death'

- Major review to be conducted by the Association for Palliative Medicine
- Inquiry will 'identify and explore concerns' over care for dying patients
- Growing fears that the system is a way of speeding up death of terminally ill
- System involves withdrawal of food and fluids as well as medical treatment

By STEVE DOUGHTY, SOCIAL AFFAIRS CORRESPONDENT

PUBLISHED: 21:58 GMT, 24 October 2012 | UPDATED: 22:20 GMT, 24 October 2012

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A major review was announced last night into the Liverpool Care Pathway, the controversial 'end of life' treatment regime.

The Association for Palliative Medicine, which represents 1,000 doctors who work in hospices and specialist hospital wards, will 'identify and explore concerns' over the system of caring for patients in their final days.

The Mail has highlighted the growing fears of patients' relatives and many doctors that the care pathway is really a way of hastening the deaths of terminally ill patients.

Possible solutions

1. Expansion of specialist hospice services is unlikely
2. Skill transfer to social and health care: 'rules of thumb'/heuristics; focus on nursing homes and home care workers
3. Advanced care planning
4. Struggling with care co-ordination between social & health services: contracts, co-location, shared budgets.
5. Informal care co-ordination: 'communities of practice'
6. Legal framework: the Mental Capacity Act 2005: assessing mental capacity, acting in best interests, least restriction

Thank you for listening

<http://www.impactpalliativecare.eu/>



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