The evidence for care coordination for people at the end of life with dementia

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Experiences from two studies

• CAREDEM - case management for people with dementia
• IMPACT - palliative care for people with dementia
Causes of death

Survival time with dementia

7.1 years with Alzheimer’s dementia, 3.9 years with vascular dementia.

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
Dementia and its difficulties

These problems…

• Ageing population, rising prevalence of dementia
• Fragmented care for people with dementia
• Budget squeeze in NHS & social care
• Difficulties with prognosis and symptom management at the end of life
• Political challenges: Liverpool Care Pathway

Suggest that we need…

• Skill transfer & smarter working (care co-ordination)

For which there is precedent….

• USA, Finland, parts of the Netherlands, parts of Spain
welcome review of the pathway to death
By DAILY MAIL COMMENT

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.

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

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.
A solution? Case Management

- Coordinated health and social care at group general practice level
- Done by a single, experienced health or social care professional already in post
- Working to a protocol (agreed procedures)
- For people with dementia and those supporting them in all settings

Precedent: The US ‘Prevent’ trial
Literature review


The potential of case management for people with dementia: a commentary
IJGP 2012 Feb 22 doi:10.1002/gps.3883
Does case management work for people with dementia & their carers? Yes!


- Callahan et al (2006) : less caregivers stress, hospital and nursing home admissions unaffected
Does case management work for people with dementia & their carers? **No!**

- Fortinsky et al (2006) : no positive effects at all

- Pinquart et al (2006) meta-analysis : reduced *risk* of care home relocation, if not a demonstrable delay

- Pimouguet et al (2010) Systematic review : *equivocal evidence for the efficacy of case management* with reference to cost and resource use
CAREDEMM & IMPACT studies

CAREDEMM
Pilot of case management, in UK, funded by NIHR
4 group practices, nurses or social worker as case manager
Recruitment of people with dementia and carers over 6 months

IMPACT
5 nation study of palliative care for people with dementia compared with people with cancer
Funded by European Union
Intervention study using quality indicators to promote change in services
CAREDEEM Outcomes

People with dementia identified from QOF searches (n =276)

In care homes (n =138)

Number assessed for eligibility (n =138)

Excluded (n =110 )
- Receiving palliative care (n = 4)
- No carer or carer uncontactable (n=24)
- Unavailable or unable to contact (n=18)
- Already case managed (n=4)
- Other, including practice reasons (n=43)
- Declined (n =17)

Number recruited (28 patients & 29 carers)
Findings

Barriers to effective case management:
• Few people with dementia recruited
• Erosion of case manager time by other clinical tasks (nurses);
• Difficulties in identifying and acting on ‘low level’ unmet needs;
• Lack of clarity over case management role;
• Poor integration with local services;
• Difficult to embed CM in primary care team (social work attachment).

Considerable variation in activity between case managers unrelated to the amount of time they had available
IMPACT

- Interviews with experts at practice, management and policy levels
- Case studies in care homes, community services, hospitals and hospices
- Literature reviews
- Interviews with carers of people with dementia
IMPACT

- People with dementia have limited access to specialist palliative care
- Division of labour/skill transfer both ways
- Care planning/staff engagement – the LCP example
- Boundaries & transitions/prognostication
- Bereavement/dying well
- Focus first on nursing homes & home care services
- Embedded support or episodic in-reach?
- Adult learning, not training
- ‘Communities of practice’ emerge before formal systems

WHO (Europe) Palliative Care – the solid facts  WHO European Office, Denmark 2004
Thank you for listening

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The views and opinions expressed here do not necessarily reflect those of the Department of Health or the NIHR, or the European Commission.