



Living and dying well with dementia in England

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Treviso, Oct 28 2011



Conclusion

People with dementia live with a terminal disease

For which they are not diagnosed until late

Often too late to be involved in decision-making



Conclusion

Inequity in end of life care for people with dementia

Need whole systems change to ensure quality end of life care for people with dementia



Overview

Policy context

Challenges



Policy context



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Inadequate care for people with dementia



Dementia strategy

A concern with **living well**
with dementia

Department of Health, 2008



17 objectives

Objective 12. Improve end of life care

Department of Health, 2008



NICE/SCIE (2006)

Evidence-based guidelines

A palliative care approach – physical, psychological, social and spiritual needs - should be adopted from diagnosis to death.

People with dementia should have the same access to specialist palliative services as those without dementia.



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End of life



4 priorities

1. Early diagnosis and support
2. Improve care in hospitals
3. Improve care in care homes
4. Reduce anti-psychotic use

Department of Health, 2010



Quality outcomes (n=9)

I understand so I make good decisions and provide for future decision making

I am treated with dignity and respect

I am confident my end of life wishes will be respected and I can expect a good death

Department of Health, 2010



End of life strategy

Talk about death and dying

People choose where to die

In their own home

Needs advance planning



End of life strategy

Assessment tools

Guidelines

Cancer-based



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Challenges



Challenges for end of life care of people with dementia

1. Identifying end of life
2. Engaging in advance care planning
3. Supporting families
4. Preparedness of professionals and practitioners



1. Identifying end of life



Symptoms at end of life

Memory

Communication

Mobility

Eating

Incontinence

Infections

Pressure sores

Swallowing difficulty



cancer

heart/lung failure

dementia

(Lynn & Adamson, 2003;
Lunney et al., 2003)

Liverpool Care Pathway for the Dying Patient

- Structured approach to care in last days of life
- Originally designed for patients with cancer
- Integrated care pathway for all settings



Liverpool Care Pathway for the Dying Patient

3 phases

1. Initial assessment
2. Ongoing assessment
3. Care after death



Liverpool Care Pathway for the Dying Patient

But for people with dementia

- Identifying last days of life is difficult
- Dementia not seen as a terminal disease
- Dying can take many years
- Focus on physical vs psycho social and spiritual care

But

- Is flexible – can be removed (Sampson, 2010)



2. Engaging in advance care planning



Advanced Care Planning

Re treatment and care

eg

Resuscitation

Antibiotics

Tube feeding



Best practice in advanced care planning

Guidelines and assessment tools

Eg

Gold Standards Framework

Preferred Priorities for Care



Gold standards framework

Identify VIP Gold person ie those in last 6-12 months

Who will benefit from palliative care

Clinical indicator checklist

Surprise question

www.goldstandardsframework.org.uk



Gold standards framework

Assess needs and preferences

Plan

clinical treatment
personal preferences

Includes an advance care plan

Reference point is cancer

www.goldstandardsframework.org.uk



Gold standards framework

high quality care

aligned with patients' preferences

improve staff confidence

ensure teamwork

home not hospital-based

www.goldstandardsframework.org.uk



Preferred Priorities for Care

What has been happening to you?

What are your preferences and priorities for your future care?

Where would you like to be cared for in future?



For people with dementia

Can people with dementia have these conversations?

When is the best time to have these conversations?



People with dementia are not diagnosed

Earlier diagnosis allows people with dementia to plan ahead to make important decisions about their future care.



People with dementia are not diagnosed

The opportunity to discuss end of life care should be provided at an early stage of their illness so they can contribute to decisions around their future care and treatment

Alzheimer's Society, 2010



People with dementia are not diagnosed

People in the early stages of dementia should have the opportunity to shape and make choices about any palliative care that they may need as the illness progresses

Alzheimer's Society

The Mental Capacity Act



Mental Capacity Act 2005

CHAPTER 9

CONTENTS

PART 1

PERSONS WHO LACK CAPACITY



Mental Capacity Act: Code of practice

Presume capacity

Right to support to make decisions

Right to make unwise decisions



Mental Capacity Act: Code of practice

If person lacks capacity, someone making substitute decisions must:

act in person's best interests

and

choose least restrictive options



If lack mental capacity

Professionals have a duty to ensure the views of people who care about the person are included

Doctors have legal obligation to act in your best interests

Unless you have made an advance decision refusing treatment (and it is valid and applicable to the circumstances)



If lack mental capacity

Lasting power of attorney

Independent advocate

Advance decisions



Advance decisions

to refuse treatment eg artificial nutrition and hydration

Specify what treatment in what circumstances

only by someone with mental capacity for period
when they lack capacity



Advance decisions

legally binding

in writing

signed

witnessed



Advance decisions – legally binding

Not for assistance with dying



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Mar 17 2008



Terry Pratchett: Choosing to die

A documentary
How he might choose to
end his life. Diagnosed
with Alzheimer's in 2008,
Terry wants to know
whether he might be able
to end his life before his
disease takes over.



Baroness Warnock: a right or a duty to die

Dementia sufferers may have a 'duty to die'

Elderly people suffering from dementia should consider ending their lives because they are a burden on the NHS and their families, according to the influential medical ethics expert Baroness Warnock.

18 Sep 2008

<http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html>



3. Support for families



Families and long term care

Risk being excluded from involvement in
relative's care

Nolan et al., 2001; Woods et al., 1999



Involving families in decisions

Need information to understand choices

Values may differ within families

Values may differ between families, doctors and staff

Best if discussed early on

Zarit & Gaugler, 2006



Involving families in decisions

Need proactive versus reactive engagement

Are not responsible for end of life care decisions, medical staff are



Supporting families

Need community nursing and general practitioner involvement

Where necessary, specialist palliative home care

Home-based emergency respite



Support for families after relative's death

Some experience little or no grief

Some experience guilt at decisions made

Adaptation and adjustment affected by relative's
quality of life prior to death

Zarit & Gaugler, 2006



4. Support for professionals and practitioners



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National Council for Palliative Care

All professionals in all settings and across all specialties need to be aware of, and able to address, the palliative care needs of people with dementia

National Council on Palliative Care, 2006, 3



Education and training

- General practitioners
- District nurses
- Care home staff
- Specialist palliative care teams
- Acute care staff
- Old age psychiatrists



Roles and ways of working

- Liaison and outreach
- Key worker



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For further information about our:

short courses | accredited education | research
consultancy | service evaluation | dementia care mapping
study days | individual modules

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