

End of life care in dementia: How can we improve this?

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Workshop aims:

1. Explore current policy and guidance
2. Examine the challenges
3. What are you currently doing ?
4. What simple changes may help ?

Multiple medical problems

Cumulative effect

Poly pharmacy

Acute illnesses

Under assessment and treatment

.....add dementia into the equation

Current UK Policy



1. ***National Service Framework for Older people.*** 2001
2. ***Palliative Care: fourth report of session.*** House of Commons Health Committee 2003-04.
3. ***Everybody's Business Integrated mental health services for older adults: a service development guide.*** Care Services Improvement Partnership, 2005
4. ***Gold Standards Framework.*** www.goldstandardsframework.nhs.uk 2005
5. ***Who Cares Wins.*** Improving the outcome for older people admitted to the general hospital: Guidelines for the development of Liaison Mental Health Services for older people. Royal College of Psychiatrists; 2005.
6. ***Improving services and support for people with dementia:*** National Audit Office, 2007
7. ***Dementia Strategy*** 2008
8. ***End of life care strategy*** 2009
9. ***End of life care for people with dementia commissioning guide (2010)***

The current UK situation

- 30% of those over the age of 60 will die with dementia
(Brayne et al 2006)
- 70% of people say they would want to die at home (only 18% do)
(Gomes and Higginson 2008)
- People with dementia are:
 - more likely to die in the acute hospital
 - less likely to receive hospice or palliative care
 - less likely to have their spiritual needs considered when they die
(Sampson et al 2006)

WHAT ARE THE CHALLENGES?

“What are the day to day challenges in providing good quality end of life care for people with dementia in care homes?”

Symptom burden

Symptoms of people with dementia compared to cancer patients in the last yr of life

People with dementia experienced similar symptoms e.g.

Confusion 87%

Pain 64%

low mood 61%

constipation 59%

loss of appetite 57%

BUT People with dementia experienced these symptoms for much longer

(McCarthy 1997)

Symptom burden

Patients with end stage dementia had a number of symptoms for which they did not receive effective palliative care

Analgesics were infrequently used & unusually in sub-therapeutic doses

Antibiotics and I.V. fluids were inappropriately used in last days of life

Dying phase was often not recognised

(Lloyd-Williams & Payne, 2002)

Symptom burden

Studies in both UK & USA suggest that people with dementia in acute hospitals, psychiatric wards and nursing homes experience high levels of 'suffering' > 60%, majority receiving sub-optimal care

(Lloyd-Williams 1996, Mitchell et al 2004, Aminoff & Adunsky 2004, Sampson et al 2006)

WHAT ARE YOU CURRENTLY DOING ?

“Can you think of examples from your own practice when you have provided palliative care for someone with dementia”


Advance care planning

“ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individuals agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care”




- To be treated with dignity and respect
- To receive palliation to reduce pain and distress where possible
- To have my family around me

Connection with other strategies:

 Department of Health

Living well with dementia:
A National Dementia Strategy



Putting People

 Department of Health


End of Life Care Strategy
Promoting high quality care for all adults at the end of life



'How people die remains in the memory of those who live on'
Dame Cicely Saunders
Founder of the Modern Hospice Movement


July 2008


 NHS

 HM Government

Carers at the heart of
21st-century families
and communities

"A caring system on your side.
A life of your own."



 NHS

Assessment of End of Life Care Needs in Dementia



Identify barriers for dementia patients and their carers to access good quality end of life care

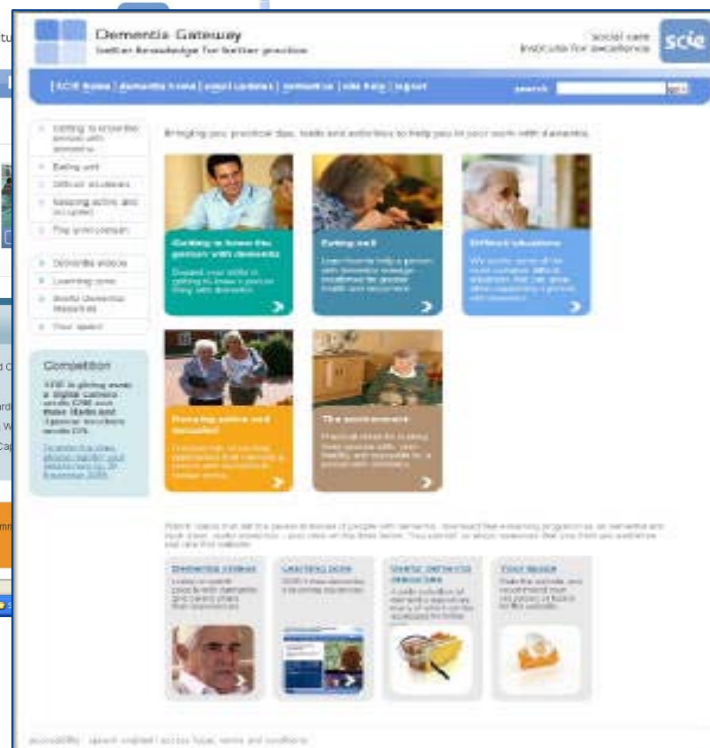
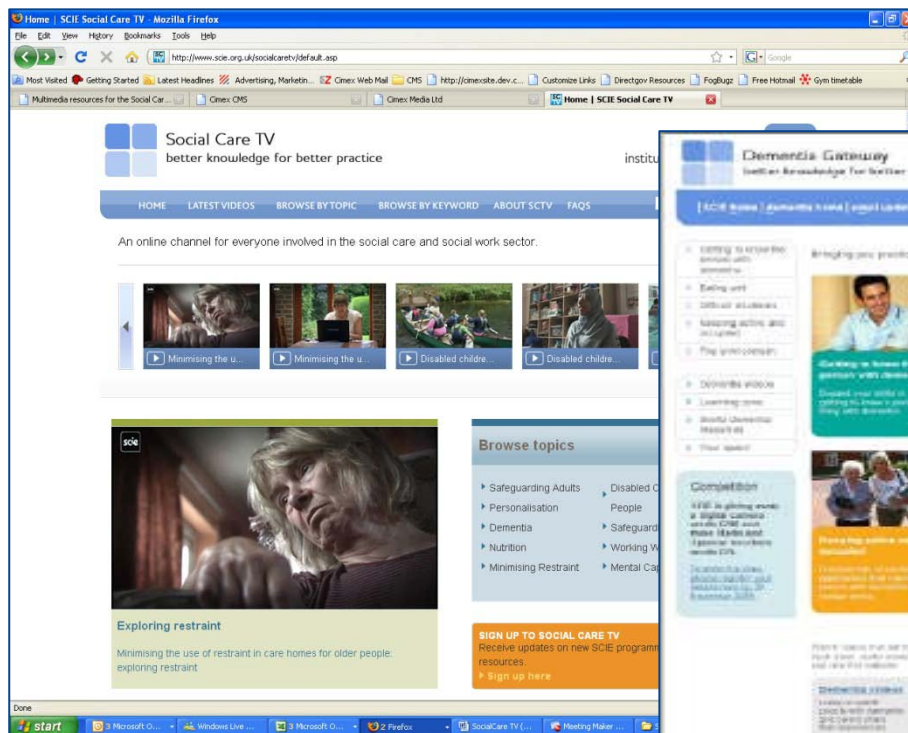
Identify cost effective improvements based on findings

The way forward/challenges

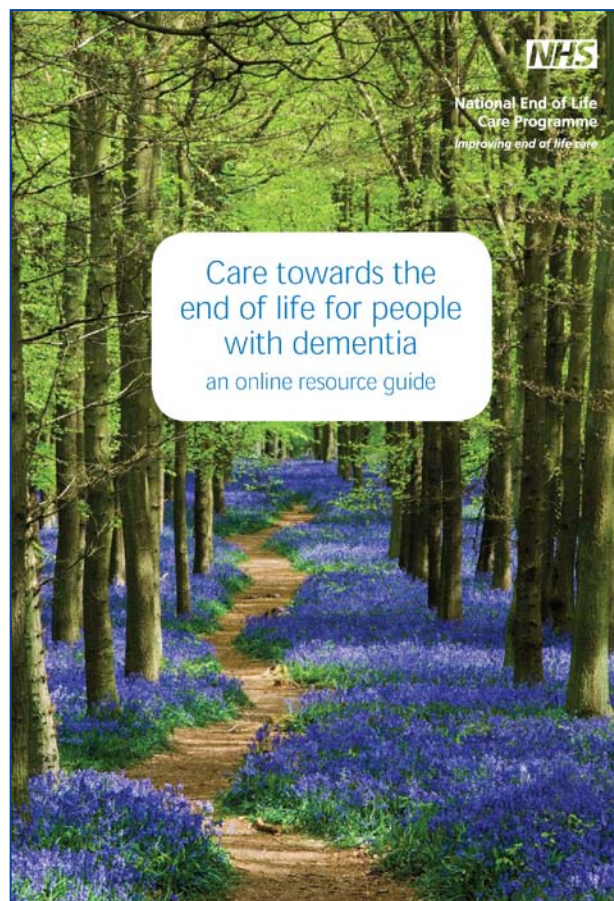
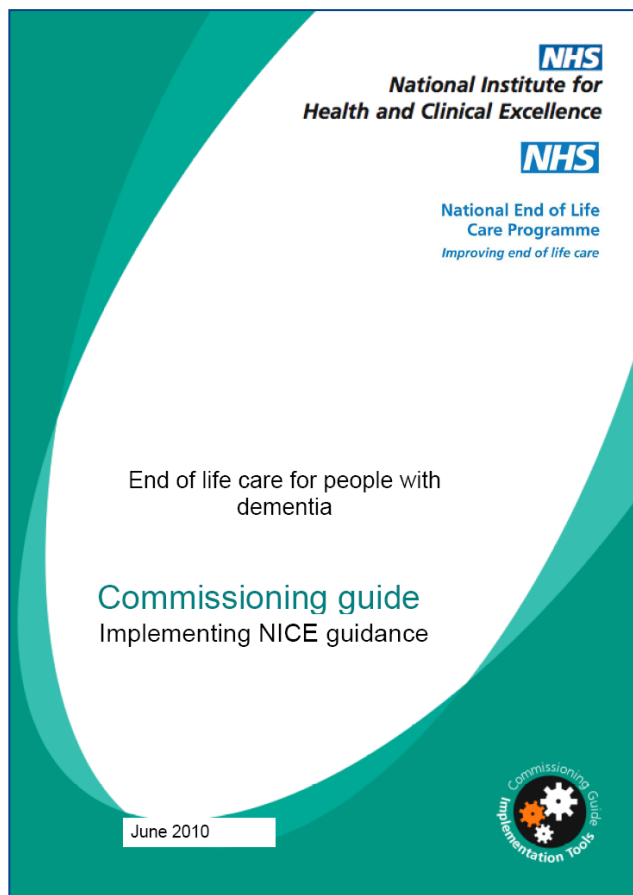
- Enabling a dementia pathway
- Preventing hospital admissions
- Enabling advance care plans
- Raising staff skills and knowledge
- Raising awareness of available services
- Improving communication between services
- Enabling access to appropriate and timely support

We have come a long way.....

social care
institute for excellence



We have come a long way.....



Questions.....



Thank you

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