



# Cruse Bereavement Care



# Valuing Life – Dying Well

**David Taylor and Catherine McLoughlin  
Presentation for the  
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**David Taylor is Professor of Pharmaceutical and Public Health Policy at the School of Pharmacy, University of London.  
Catherine McLoughlin is a student at the London School of Economics who worked with The School in the summer of 2008**

# This presentation

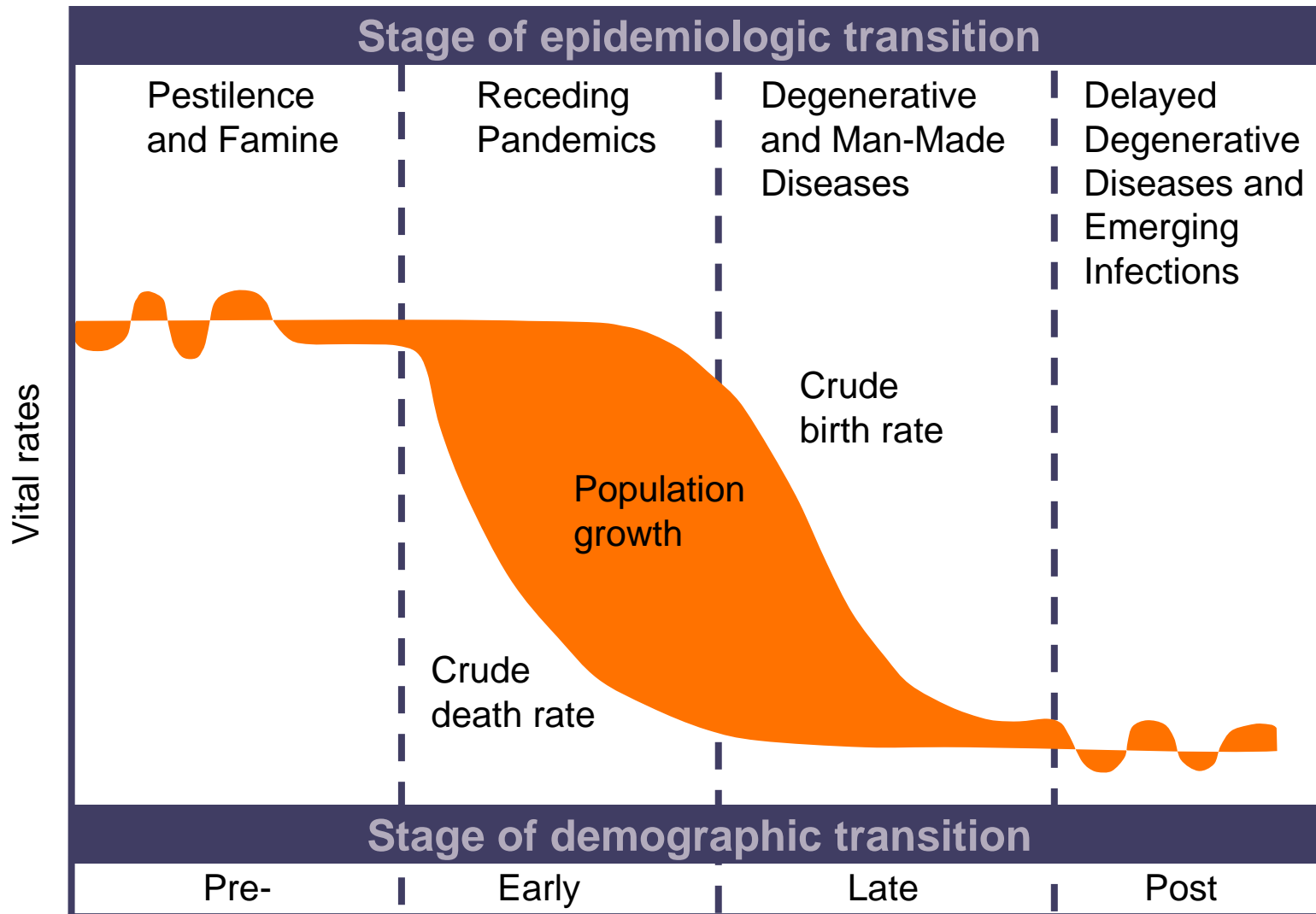
- Care transition – changing patterns of illness and health care requirement
- Previous findings, published by Marie Curie Cancer Care in 2003 in *Valuing Choice – Dying at Home*
- Current developments, including the End of Life Care Strategy and the Darzi Review
- Future issues – making a reality of informed choice



**Professor Mike Richards**

# Introductory comments

- There is positive value in openly and realistically accepting death, while also respecting empathetically individual sensitivities, beliefs and coping strategies
- There is a powerful case for investing both private and public money in good quality end of life care, even if the models used by some health economists may not fully be able to demonstrate this
- Making a reality of choice and respecting the autonomy and dignity of individuals inevitably involves others doing things we ourselves do not necessarily want or approve of. It may, for instance, allow dying people to determine not only the place but also the time of their last breath.



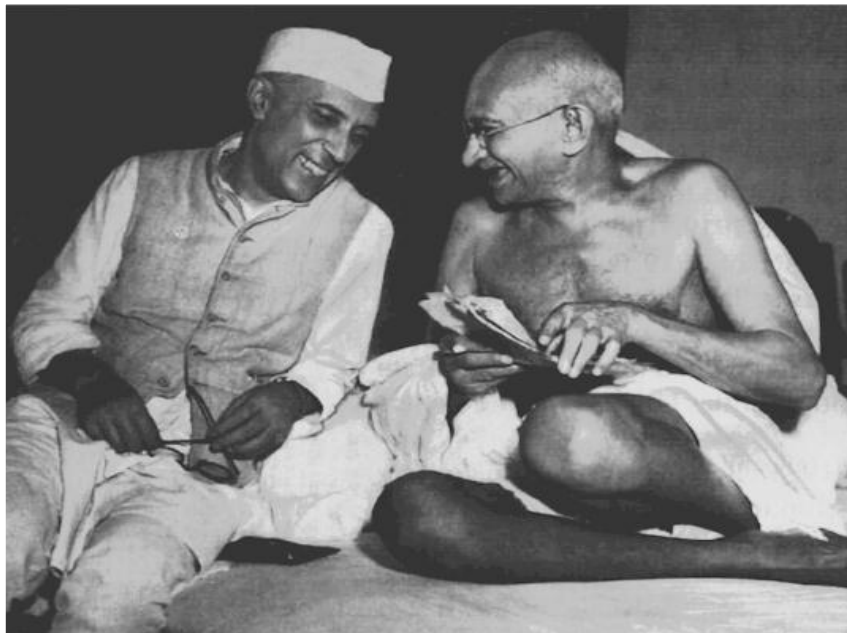
# Stages of health development

- Demographic transition
- Epidemiological transition
- Care transition



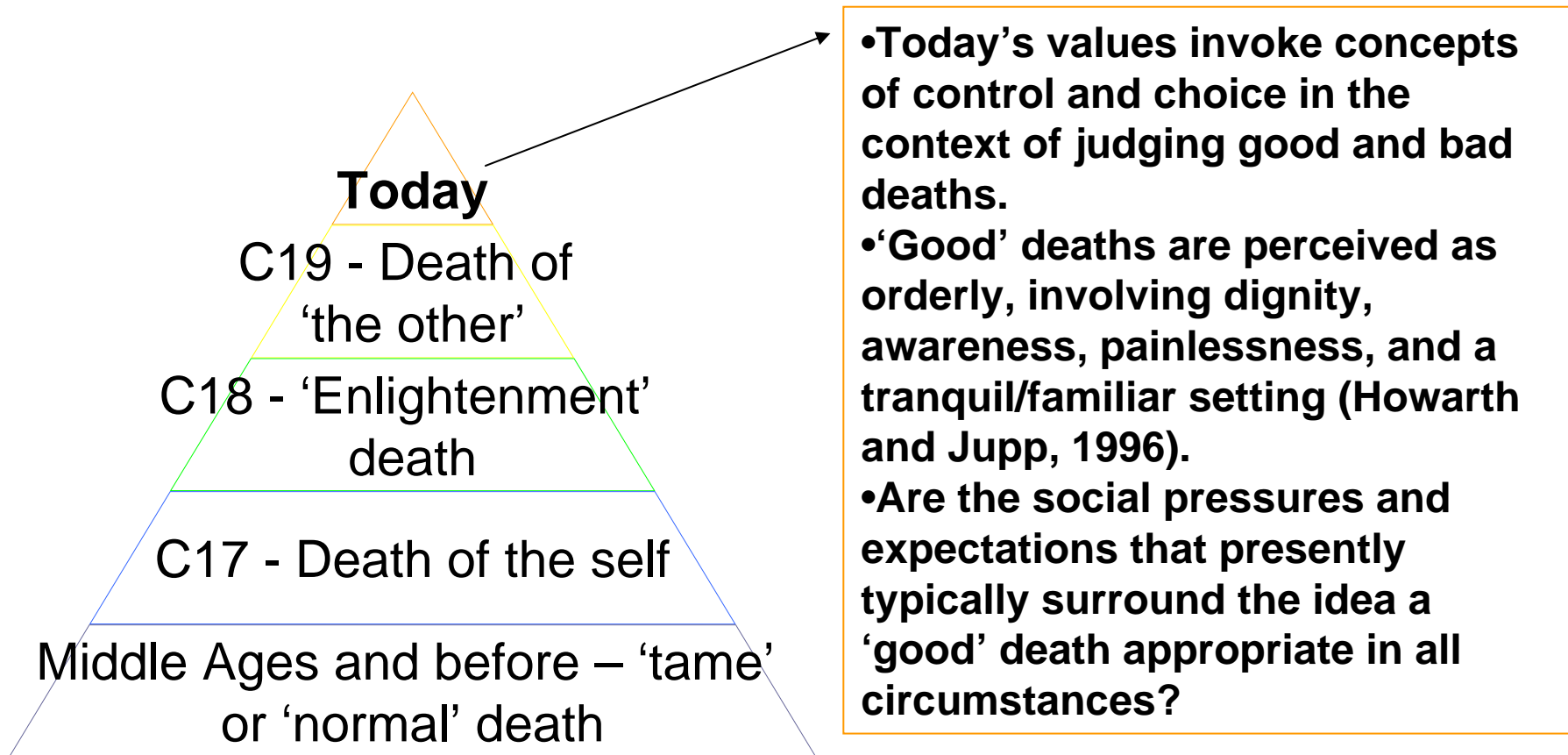
King James 1 granting the British Apothecaries their first Royal Charter in 1617

# Later stages of care transition include...



- Increasingly assertive consumerism in health care
- Decreased tolerance of health inequalities
- Decreased social distance between health professionals and service users
- Increased recognition of the role of self care in (public) health improvement
- A shift of care quality management away from exclusive control
- Changed attitudes towards ageing, dying and death

# How have attitudes towards death changed?



As societies develop, the perceptions, processes and rituals of death also evolve

*Source: Health and Illness in a Changing Society, Bury, 1997.*

# *Valuing Choice – Dying at Home*

Key findings included:

- Most people would prefer to die at home. But even amongst those with cancer under a quarter actually do so.
- Support from organisations such as Marie Curie Cancer Care can effectively protect individuals from needless distress and indignity
- We calculated that in the medium to long term every £1 spent on ‘hospice at home’ services should release £2 for use on other forms of hospital care
- We called for an extra £75 million of public money to be spent in England on better services for end of life care at home

# Preference and place of death.

Despite estimates that around two-thirds of people would prefer to die at home, the majority are still dying in hospital.

Year	Place of death			
	NHS Hospital	Care Homes	Home	Hospices
2001*	56%	21%	19%	4%
2008**	58%	20%	18%	4%

One recent estimate suggests by 2030 a little under 10 per cent of people will die at home (Gomes & Higginson 2008). This projection may or may not prove accurate. But it nevertheless highlights the need to ensure that high quality end of life care is available in every setting.

\*Office of National Statistics 2001

\*\* End of Life Care Strategy 2008.

# The Current Situation

Lord Darzi's Next Stage Review focused on End of Life Care as one of its key pathways.

The End of Life Care Strategy directly addresses the needs of the patient and carer:



- The opportunity to **discuss, record** and be **supported** in personal needs & preferences.
- Access** to specialist advice, & specialist palliative care outreach services.
- Emotional & practical **help for carers**; emergency plans and support after death.
- Services will be monitored and assessed to ensure quality & **patient's experiences** will be evaluated (VOICES) to **inform future care**.

Source: End of Life Care Strategy, July 2008.

**Providing better quality end of life care has become a more clearly recognised objective. But in practice service delivery still needs to be improved**

# What are we spending?

▪The Government pledged to double public investment in specialist palliative care to in its 2005 election manifesto. At that time outlays were estimated at £180mill = £130m spending found in 2000 + £50m boost from 2003/4 NHS Cancer Plan. A 2006/7 survey put English PCT spending on hospices and specialist palliative care at £250 million

Planned increases on PC spending

Year	Revenue	Capital	Total
2009/10	£80m	£8m	£88m
2010/11	£150m	£48m	£198m

Source: End of Life Care Strategy 2008.

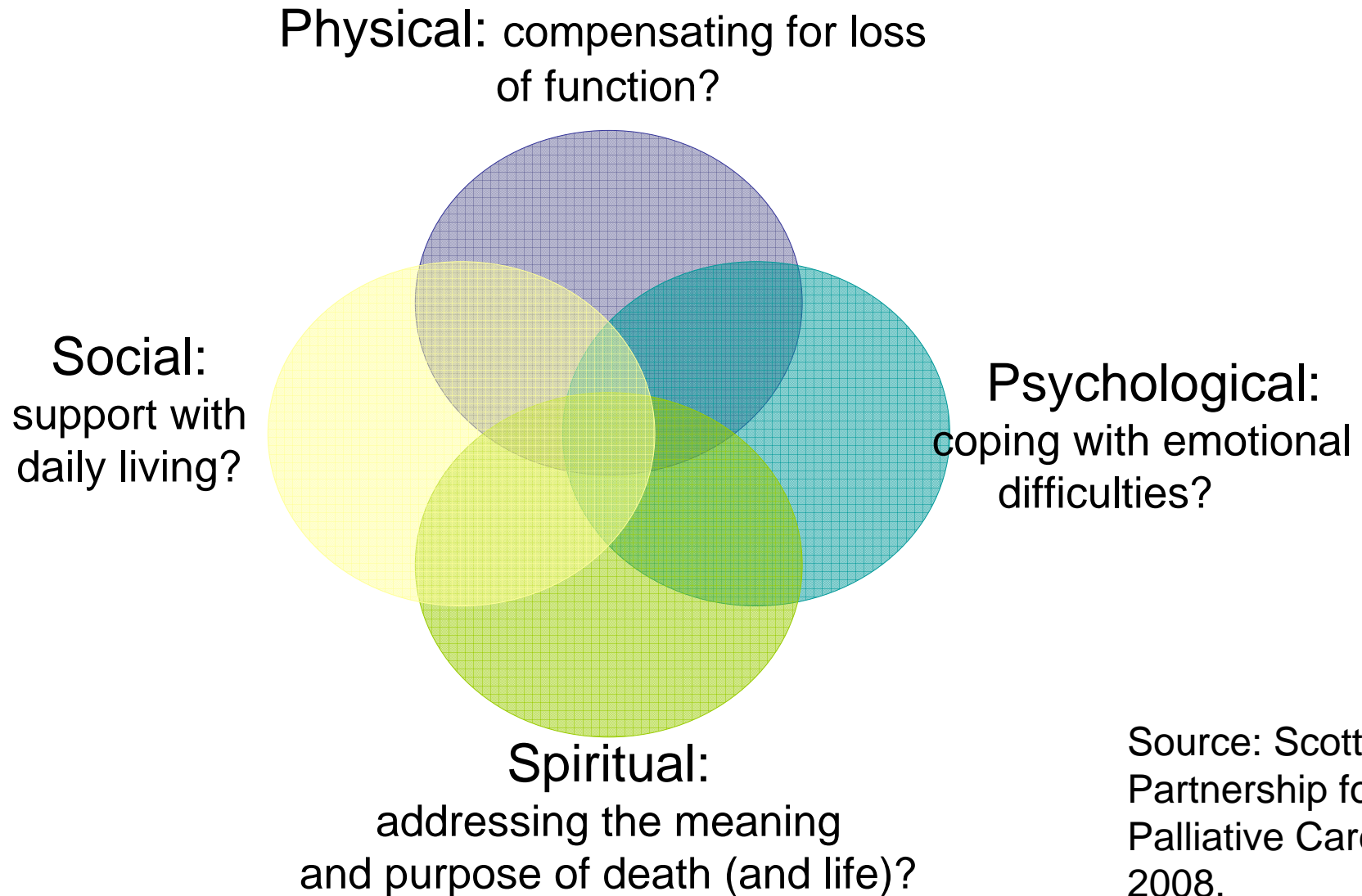
In 2000 'third sector' funding for palliative care was in the order of £170 million over and above NHS input. Total community investment in end of life care is probably > £1 billion

= £286m  
reported additional  
money.

# Issues for the Future

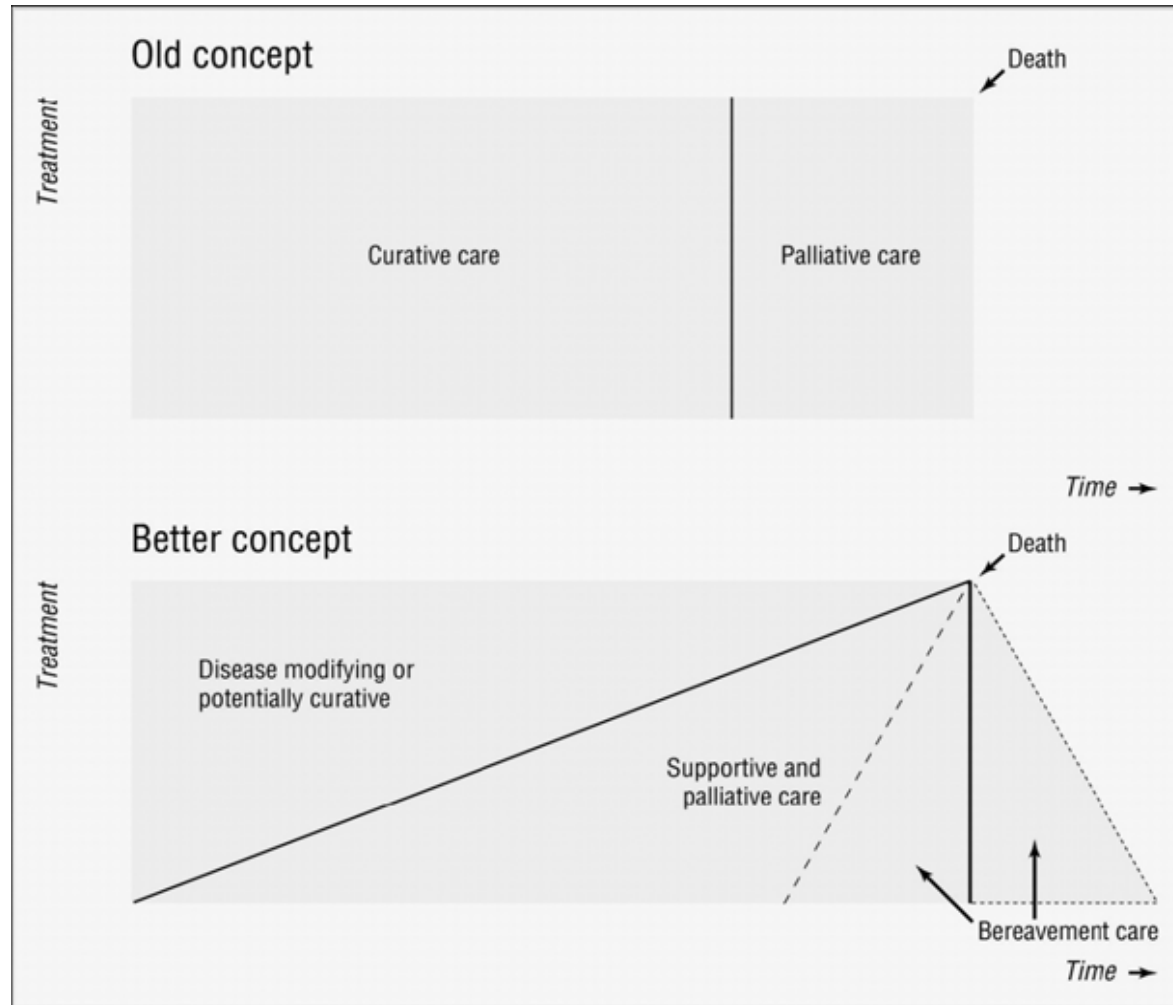
- Developing constructive understandings of death and dying in 'post-modern' societies
- Managing grief
- Building further our knowledge of what different sections of the community genuinely believe and value, and exploring the changing role of social institutions like general practice
- Defining palliative care - what is it, who needs it, and when should it start?
- Improving end of life services – establishing appropriate quality standards and assessing which delivery models are most cost effective
- Providing effective education and support for workforce members and carers

# What is Palliative Care?



Source: Scottish Partnership for Palliative Care, 2008.

# When should palliative care start?



The transition to palliative care requires sensitivity to effectively meet changing needs.

Source:  
Murray et al, 2005

# Who needs palliative care?

- The National Dementia Strategy and Implementation Plan focuses on improving awareness, intervention & quality of care for those with dementia.

**It has been forecast that approaching 2 million people in the UK will have dementia by 2051**

- The care of older persons exemplifies the challenges, regarding palliative care, that the NHS faces in the C21st.
- Developing **integrated services** that provide both health and social care is vital to this challenge.. For example, the local palliative care dementia group in Whittlesey includes a local GP who conducts regular ward rounds at care homes (EoLC Strategy, 94).



**Groups of people in need of effective palliative care include not only cancer patients but those with conditions such as heart failure and some forms of Parkinsons disease**

# Discussing death and establishing care pathways

- The Childhood Bereavement Network (CBN) suggests that the majority of young people will be bereaved of someone close to them by the time they are sixteen
- Anticipatory grief amongst carers is an example of an issue requiring careful attention

## End of Life Care Pathways

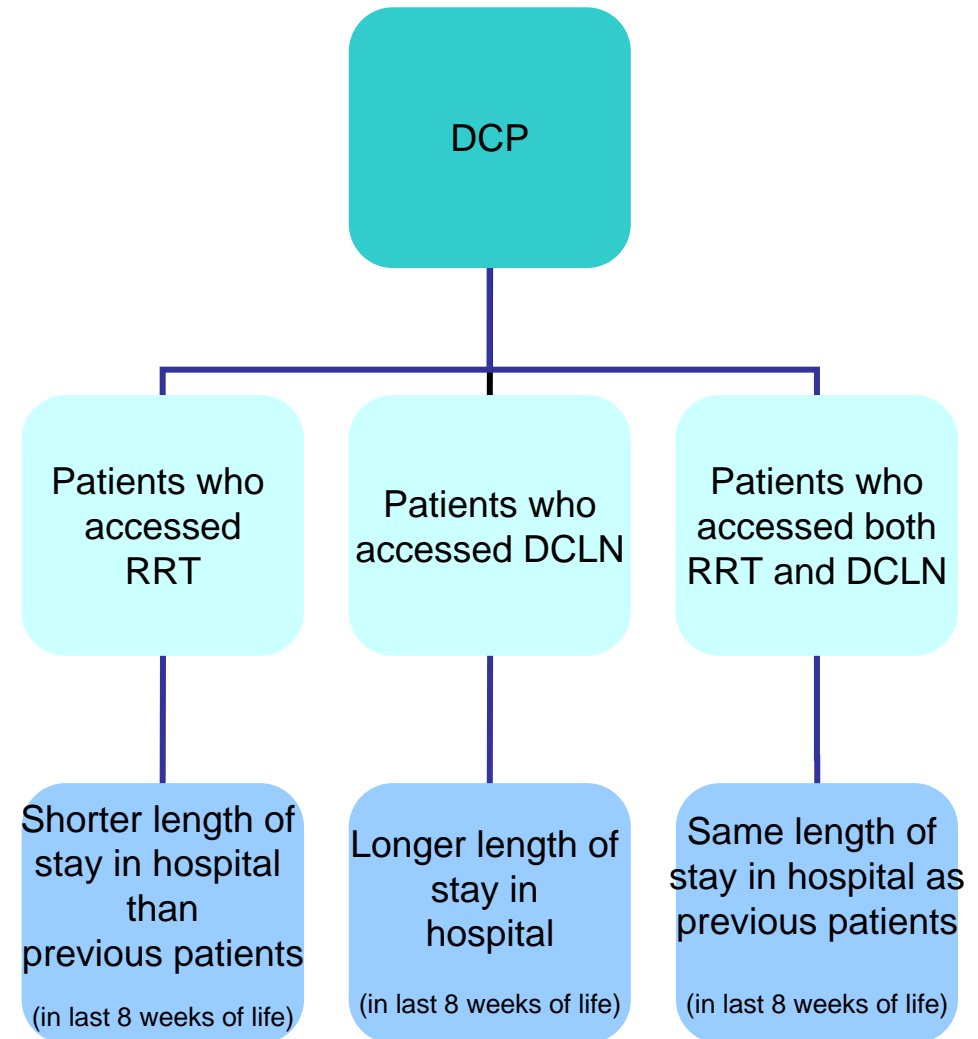
Each pathway is individual and is influenced by many different needs/preferences.

Whilst there is no simple way to define the start, each pathway includes the discussion, assessment, reviewing, co-ordination and delivery of high quality care.

Source: End of Life Care Strategy.

# Assessing what works

- The King's Fund report *Improving Choice at End of Life* (2008) evaluated the Marie Curie Delivering Choice Programme in Lincolnshire.
- It concluded that the programme 'significantly increased' the number of deaths at home and kept combined costs constant
- Main finding = **combined** impact of multiple services provides the best support for patients with complex needs.



(For patients dying of cancer)

# Educating and Supporting Staff and Service Users

## Why is E&S important?

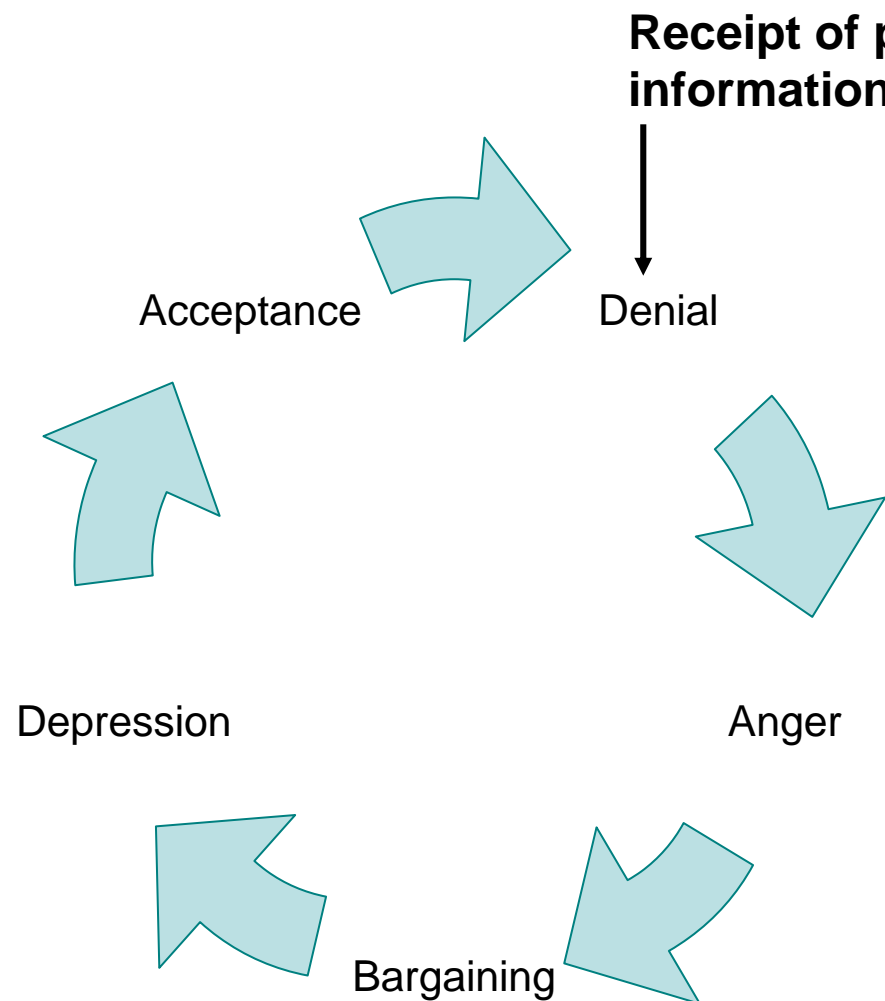
- Staff need to recognise if they are not able to provide support.
- A lack of information about diagnosis/prognosis is found to contribute to high rates of depression in patients and families. (Scottish Partnership for Palliative Care p.22/23)
- Advanced care planning needs to be tailored to a patient's specific ethnic views.

Support needs to be culturally sensitive, but also enable patients, carers and staff to interact within consistent framework of knowledge and values to prevent negative outcomes

## How do we provide structures E&S?

- The Palliative Care Team at King's College Hospital delivers education to healthcare professionals and palliative assessment to patients.
- EoL Care Strategy outlines a broad programme of workforce development, across all staff groups.

# Experiencing and Managing Grief



Grief, like most other important life experiences, is process rather than a single event through which our needs – and selves – change

## Anticipatory Grief

- Involves a sense of loss in advance of death, and is not primarily focused on the dying person?
- May affect dying individuals as well as carers?
- Is rare?
- Might reduce end of life care quality?

# Other issues

- Improving environments for care at the end of life
- The importance of recognising diversity, and responding to individual need
- The role of mental health care Trusts and practitioners
- What we want of our family doctors, and the extent to which we as a society are managing or mis-managing our GPs and wider primary care services
- The role of pharmacists in end of life care



# Conclusion

- Our society is through the leadership of good individuals and robust private and voluntary institutions improving end of life care. The NHS has not lead reform, but will hopefully be part of a better future.
- However, there is no room for complacency. Success requires both individuals and institutions to be vigilant and determined, and to address existential and philosophical questions as robustly as they do accounts and day to day practical issues.
- Achieving a good death is arguably the last great challenge for each successful identity. I believe that user focused end of life care must ultimately involve helping those who wish it to control not just the place but also the time and nature of their final conscious actions.

**David.Taylor@Pharmacy.ac.uk**