End of Life Care
The facts and challenges

Professor Edwin Pugh

Key Drivers for Action

- Darzi
- SHA End of Life Strategy *June 2008*
- National End of Life Strategy *July 2008*
- National Audit Office End of Life Care *Nov 2008*
- Quality Markers *2009*

Changing Patterns of Disease

1900

- **Age at death**
  - 46
- **Top 3 causes**

1. Infectious disease
2. Accident
3. Childbirth

- **Disability before death**
  - Not much

2000

- **Age at death**

78

- **Top 3 causes**

1. Cancer
2. Organ failure
3. Frailty/ dementia

Disability before death

- 2-4 years

Place and Preferences of the Public

- **Place** **(Middlesbrough)**

- 61% hospital
- 21% home
- 13% care home
- 3% hospice

- **Preferences**

- 15%
- 60%
- 0%
- 15%

Who dies where and with what in Middlesbrough?

Category	Hospital %	Hospice %	Home %	Nursing/ Care Home %
Neoplasm	52	12	28	8
Circulatory system	62	0.1	23	13
Respiratory system	70	0.2	16	14
Nervous system	48	0	11	40

Source:Office for National Statistics 2006

Middlesbrough 1382 deaths 2006

The North Tees and Hartlepool Hospital Perspective

- 1600 deaths a year
- 97% of people who died were admitted as an emergency
- Around one quarter of hospital deaths are people aged under 70 and almost a half are 80 or over
- Around one quarter of hospital deaths occur within the first three days of a stay
- Admissions where people have died equate to **21248 (9.8%)** bed days
- There is national projected increase in deaths of 20%

The Care Home Perspective

- 1 in 5 people over 65 will die in a care home
- On average 50% of residents die within 2 years of admission *(Hockley et al 2004)*
- Increasing frailty of residents
- 27% residents confused, incontinent and immobile *(Bowman et al 2004)*
- Isolation of care Homes to training and lack of palliative care knowledge *(Gibbs 1995, Hall et al 2002)*

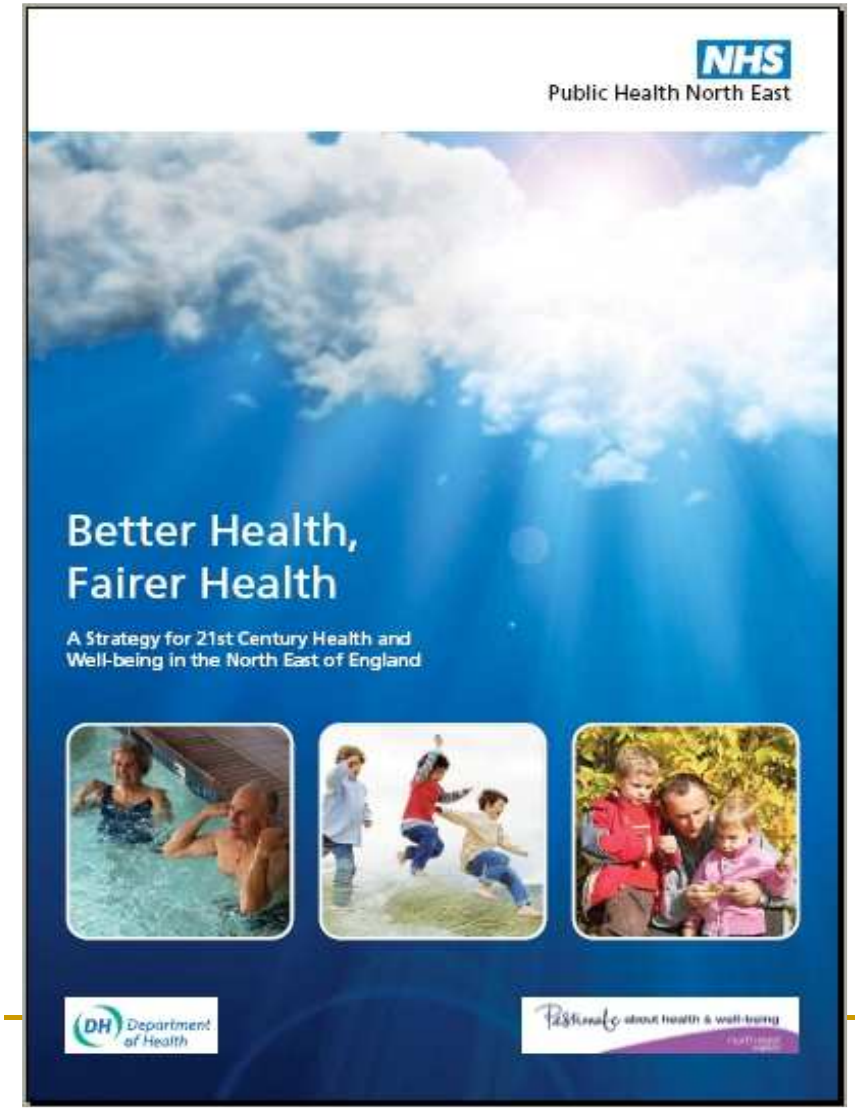
The Care Home Scenario

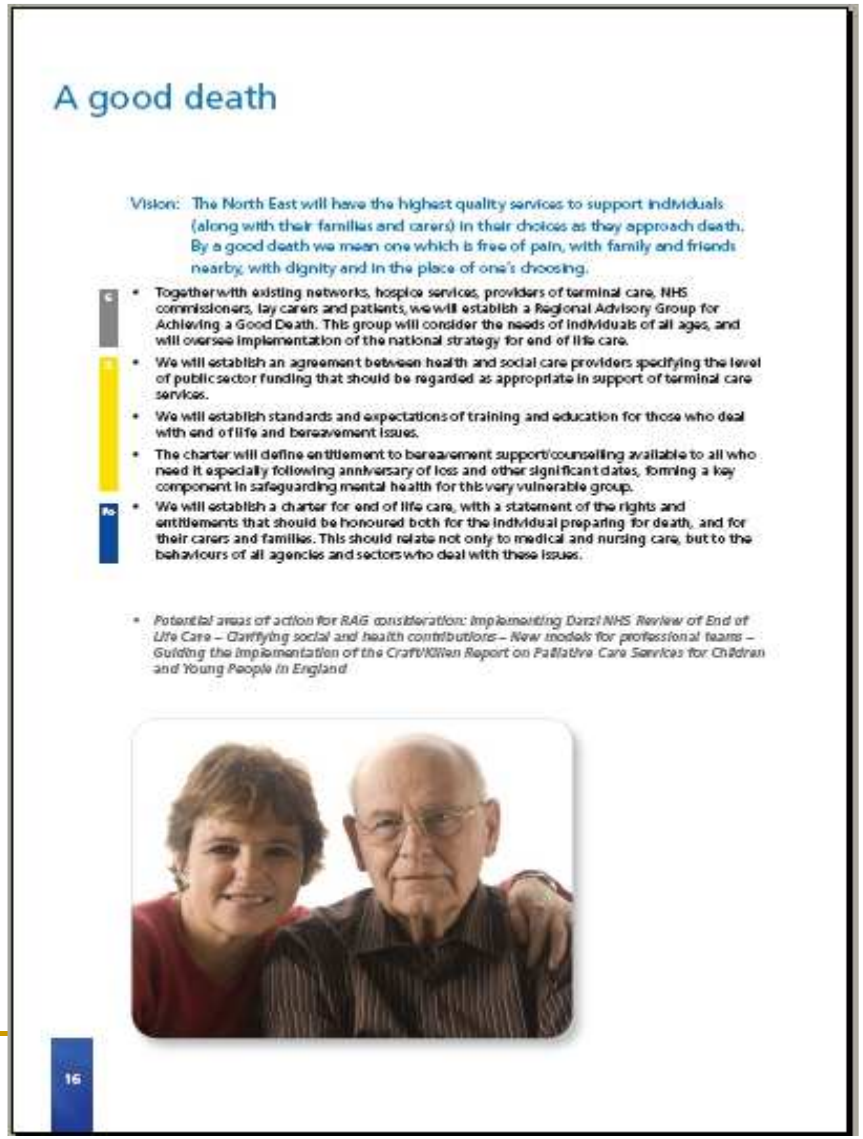
- One quarter of residents die in hospital
- Wide variations between care homes
- 59% of those admitted could have remained in care home with extra support.

National Audit Office
End of Life Care
November 2008

Towards a *Good Death*

Taking a Public Health Approach





What is a *Good Death*? A new vision for the north east

"*The North East will have the highest quality services to support individuals (along with their families and carers) in their choices as they approach death.*

By a good death we mean one which is free of pain, with family and friends nearby, with dignity and in the place of one's choosing."

Death and Dying is:

- a normal part of life
- more than a medical responsibility
- a Public Health and Societal Issue
- a responsibility of a ‘compassionate community’

Features of a Compassionate Community

- Acknowledges end of life care as the responsibility of the wider community and organisations
- Involves end of life care in local government policy and planning
- Offers people a wide variety of supportive experiences, interactions and communication
- Has a strong commitment to social and cultural difference
- Provides easy access to grief and palliative care services

Better Health, Fairer Health 'pledge'

"We will create a charter for end of life care, with a statement of the rights and entitlements that should be honoured both for the individual preparing for death, and for their carers and families. This should relate not only to medical and nursing care but to the behaviours of all agencies and sectors who deal with these issues."

Death and dying in the north east now

- death becoming medicalised
- over-use of expensive hospital facilities
- death a taboo subject
- wider role and responsibilities of non NHS organisations and society at large not addressed

Action so far…

- Draft charter produced by multi-agency regional advisory group
- 2,500 responses to public and organisational consultation exercise
- public awareness and social marketing campaign
- research into societal attitudes and behaviours
- joint working with the new national *Dying Matters* coalition
- national and regional launches

A good death
Death scares me and thinking about it scares me even more.
Don't miss out on a good death.
Go to agooddeath.co.uk
A good death
Time to think
I'm dying, my family won't talk about it.
miss out on a good death.
agooddeath.co.uk
A good death
Time to think
How do I prepare for death so I can carry on living?
Don't miss out on a good death.
Go to agooddeath.co.uk
A good death
Time to think
NA56 SZV

Key to Success

- support by the public
- support by NHS, LAs, VCS
- ownership and backing by all agencies
- fit with NHS Constitution

Personal Views: Challenges for Agencies and Society

- Major shifts in expectations and culture in society ……
- …….and organisations
- A ‘Compassionate Community’ approach

Role of the Charter

- Can we get statutory agencies and local organisations to adopt of the Charter?

Practical Questions of Service and Society

- Is social and health care provision seamless?
- Do we provide 24/ 7 support?
- Do we have compassionate human resource policies for people with illness and carers?
- Are we planning to enable choice of place of living, dying and death?
- Is end of life care a core skill of staff?
- Are we creating compassionate communities?

Thank you